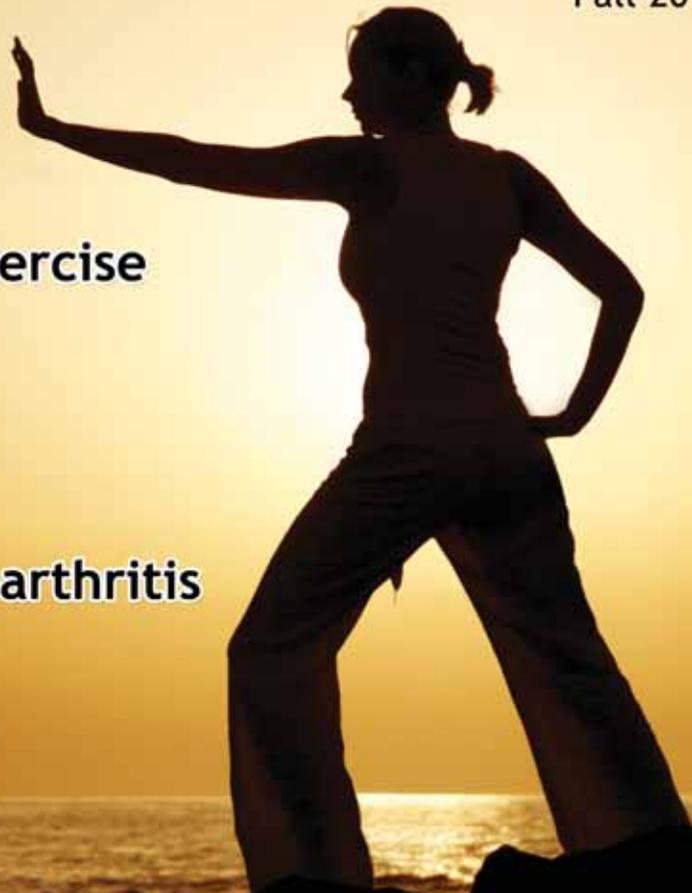


# SPONDYLITIS PLUS

Fall 2014

**Tai Chi:  
A Tried and Proven Exercise  
for Centuries**

**Overheard:  
Exercise and Spondyloarthritis**



 **Spondylitis  
Association  
of America™**

**SPONDYLITIS ASSOCIATION  
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*To be a leader in the quest to cure  
ankylosing spondylitis and related  
diseases, and to empower those  
affected to live life to the fullest.*

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medications or products for spondylitis,  
and always advises that you seek the  
counsel of a physician before initiating  
any treatment for spondylitis.*

**ON POINT**



*Dear SAA Members & Friends,*

The recent good news for the amyotrophic lateral sclerosis (ALS) community is that, as of this writing, the Ice Bucket Challenge has raised >\$100M in donations from over 2 million individuals. This viral effort also demonstrates the amazing charity and “let’s fix it spirit” in this country when individuals are presented with a challenge.

ALS is an unforgiving disease that is also misunderstood and gets little attention. As reported in the medical literature, there have been no scientific breakthroughs at least since 2007. Thus, one can only hope that this focus will be sustainable and will lead to change for those affected by this debilitating and life threatening disease.

Spondyloarthritis (SpA) is also a serious disease that is under diagnosed and is often an invisible condition to those uninitiated in its challenges. Furthermore, the media and the general public for the most part do not think of arthritis as being a serious disease. We know differently. SpA for some individuals can and does leave the devastation of emotional and physical pain in its wake. We are making progress but there is much work to be done.

While we have not yet seen millions of dollars in volunteer fundraising in our community, we have experienced a wonderful and significant uptick in volunteerism and fundraising during the past four years in support of SAA and those we serve. We thank our own volunteers and amazing individuals who have stepped up to raise awareness and funds, and who have worked hard in support of our mission. Those individuals also recognize a challenge and let nothing stand in their way.

So, now it is time for the media, medical community, politicians and high profile celebrities to step up and to recognize that there are other underserved and misunderstood little known forms of serious chronic disease that need your support. These would include Ankylosing Spondylitis and Related Conditions!

Thank you for listening,

~Laurie M. Savage  
Executive Director, SAA

# CONTENTS



## FEATURES

4 | | A Look At The Evidence:  
The Benefits Of Tai Chi



6 | | Tai Chi: A Tried and Proven Exercise  
for Centuries



14 | | Overheard: Exercise and Spondyloarthritis

## ARTICLES

10 | 10 Tips for Managing an AS Flare

18 | Yoga & AS: A Love-Hate  
Relationship

## ALSO IN THIS ISSUE

3 | Reader's Forum

17 | Internet Rock Festival: Banding  
Together for BlowUpRadio.com's  
Annual Spondylitis Benefit

### Letters:

**Editor's Note:** The article, "Crazy S#@% Doctors Say" in the Summer 2014 issue of *Spondylitis Plus* drew quite a response. Many of you chimed in with your own crazy doctor quotes. What follows is a selection of your submissions.

**Re: Crazy S#@% Doctors Say #1**  
Having dealt with spondylitis since 1976 and having it diagnosed immediately by doctor, I am astounded to read about the problems the misdiagnosed spondylitis sufferers are still dealing with at this time.

I am simply writing this note to reassure others that, despite setbacks, they can still have a most fulfilling career and they should search till they find a satisfactory doctor to give them the aid they deserve. To make that much possible, I call on the medical profession to give a much higher priority to educating doctors about spondylitis.

Sincerely,  
Warren C.

### Re: Crazy S#@% Doctors Say #2

Not having been diagnosed yet with AS, I saw a few doctors who ALL had the same opinion: "All you're doing is looking for painkillers".

Me: "Of course I am. I hurt. Every day."

Doctors: "Well, go to rehab and see me when you are finished."

Really? So, I went to a rheumatologist who immediately said (FINALLY), "First, let's see WHAT we're treating here," and he proceeded to take a few vials of blood, one of which was for the HLA-B27 test. Of course, that came up positive and I finally had something to go on.

Thank you,  
Eileen T.

### Re: Crazy S#@% Doctors Say #3

Recently I went searching for a new Rheumatologist. One fellow said to me, "You're 73 years old. The damage has been done. Go home and take Tylenol." Needless to say that was the one and only time I saw that guy. I'm still searching.

Bob E.

### Back In Action DVD

Just tried my Back in Action DVD from @spondylitis so far so good... some are hard work! Definitely what I was hoping for.

Thanks!

Linney C. ~Via Twitter

**Editor's Note:** Glad it is working for you, Linney! This issue is exercise focused. As you may know, exercise is a cornerstone of treatment for spondyloarthritis.

Our exercise DVD is available for purchase online at [StopAS.org/store](http://StopAS.org/store) - or call us toll free at 1-800-777-8189.

### LETTERS TO THE EDITOR

Question, comment or concern? We want to hear from you!

Please send letters to:  
[chris.miller@spondylitis.org](mailto:chris.miller@spondylitis.org)  
Letters to the Editor/SAA  
P.O. Box 5872, Sherman Oaks, CA 91413

Please note that we reserve the right to edit for space and clarity.

# Tai Chi & Spondyloarthritis

*Editor's Note: According to the Mayo Clinic, Tai Chi is "an ancient Chinese tradition that, today, is practiced as a graceful form of exercise. It involves a series of movements performed in a slow, focused manner and accompanied by deep breathing... a noncompetitive, self-paced system of gentle physical exercise and stretching." For more information, and a personal story of the effectiveness of Tai Chi, see Wilson McCoy's article on page 6.*



## A Look At The Evidence: THE BENEFITS OF TAI CHI

“**I**n the last two decades, a growing body of research aimed at investigating the health benefits of Tai Chi in various health conditions has been recognized in the literature.” This statement comes from a paper published in 2012 in the journal, *Regional Anesthesia and Pain Medicine*. Indeed, if you look at the results from a simple search for “Tai Chi” in the US National Library of Medicine / National Institutes of Health website, PubMed.com, there were about a dozen studies per year on Tai Chi pre-2000. In the last decade, however, studies on this form of “martial art” have increased exponentially. In 1999 PubMed only lists 17, but in 2013 there was a high of 175.

The paper (a history and literature review on the subject), “Tai Chi and chronic pain” goes on to state, “Tai Chi seems to be an effective intervention in osteoarthritis, low back pain, and fibromyalgia.”

In December of 2008, a study titled, “Tai Chi for disease activity and flexibility in patients with ankylosing spondylitis—a controlled clinical trial” was published in the journal, *Evidence-Based Complementary and Alternative Medicine*. The paper states that, “The Tai Chi group performed 60 min of Tai Chi twice weekly for 8 consecutive weeks and 8 weeks of home-based Tai Chi, after which the group showed significant improvement in disease activity and flexibility compared to the control group.”

Looking at the mounting number of studies, Tai Chi has been examined as to its efficacy in osteoarthritis, functional fitness in older adults, Parkinson’s Disease, rheumatoid arthritis and a litany of other conditions. According to the paper, “Tai Chi and yoga as complementary therapies in rheumatologic conditions”, published in 2012 as well, “There is evidence that Tai Chi and yoga are safe, and some evidence that they have benefit, leading to reduction of pain and improvement of physical function and quality of life in patients.”

Also in 2012, the American College of Rheumatology made recommendations for Tai Chi in knee osteoarthritis and similar recommendations in osteoarthritis overall.



That said, each of the above papers issues its own cautionary disclaimer. Overall, each states that larger, randomized controlled trials are necessary to endorse a full recommendation of Tai Chi in treatment. Even the controlled study on ankylosing spondylitis states that, “We cannot completely discount the possibility that the placebo effect was responsible for the improvement.”

On the whole, the evidence looks positive. As more trials get underway, time will tell how effective Tai Chi is in helping to treat spondyloarthritis.

### References & Further Reading

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# Tai Chi:

## A Tried and Proven Exercise for Centuries

By Wilson McCoy.

**Editor's Note:** Wilson is SAA's former leader of The Woodlands TX Spondylitis Educational Support Group.

"Hi, my name is Wilson McCoy and I have ankylosing spondylitis (AS). I am 71 years old and have had the disease for several years before being diagnosed July 2005." Too often we hear these words at each support group meeting. The new attendees are coming to gather as much information on spondyloarthritis as they can while the older members of the group are there for support and additional information. I hope the following information will be of benefit to all who have ankylosing spondylitis or related condition.

I would like to begin with a brief history of Tai Chi, which goes back to the Song Dynasty (960-1126 AD). The roots of this balanced art can even be traced back to the 4<sup>th</sup> century BC. In its early stages, Tai Chi was developed and

practiced in Taoist and Buddhist monasteries. Combining focus on health, meditation and martial arts, this form of exercise sought to create mental and physical balance for the trainee. Although Tai Chi's benefits seem clear today, it did not gain widespread popularity as a healing exercise until the early 20<sup>th</sup> century.

Tai Chi is many things but perhaps can best be described as a form of slow, soft and graceful physical and mental exercise combined with breathing and relaxation techniques. It is truly a holistic (mind, body and soul) approach to exercise. The surroundings, music, clothing, and time of day are considered to be of equal importance, but still, Tai Chi can be done by anyone anywhere.

**"I needed to find a way to keep my body and mind in shape."**

Regular practice of Tai Chi, being a low-impact to no-impact mind-body exercise, has been found to provide significant health benefits such as an increase in energy levels, as well as an increase in flexibility and joint movements. It strengthens the cardio-pulmonary system, increases muscular strength, improves mental focus, improves balance - thus reducing the chance of falling, detoxifies the body, reduces the chance of back pain by relaxing the back and hips, and promotes better sleep. With all of these benefits, why is everyone not *playing* Tai Chi? ("playing" is the Chinese term for practicing Tai Chi)

In the mid-1980s my back pain became severe enough to require a regular dose of NSAIDs. Multiple steroid shots seemed to help for a short time but the pain always returned. Still, I would have no answers for the next 20 years. Finally in July of 2005, I was diagnosed with ankylosing spondylitis. I was relieved to hear what the problem was but yet worried as to how to manage it for the rest of my life. More frightening was the fact that



there was no cure for the disease. After wearing a Miami “J” cervical collar for 18 months, I decided that surgery was the only solution to the pain and thus had my C1-C6 fused in November of 2006. In 2007 my rheumatologist started me on one of the biologics.

Having AS limited my physical activities. I have been a Registered Professional Land Surveyor since 1971 working in the field throughout the United States and foreign countries. Being inactive was not my style. I needed to find a way to keep my body and mind in shape. During much of my research for solutions, I kept running into the words ‘Tai Chi’. Was this what I had been looking for? I signed up at our local recreation center that was starting a Tai Chi class for seniors. This was a turning point for me.

The first few weeks were doable, that is to say, I was able to perform some of the movements after much practice but still had limitations because of my cervical fusion. My sifu (teacher) worked with me knowing that I had limitations. He told me, “In Tai Chi, an individual needs only to do what they are able to do. Do not force your body beyond its limits.” True, I could not lift my leg as high as the Radio City Rockettes, but over time I got half way there.

During the first few months, I was able to achieve balancing on one leg while kicking the other to the front or side. I kept practicing until I was able to perform the 8-Step Form, which is a form designed for seniors. Since then I have been learning additional Tai Chi forms and movements.

I have learned how to stand erect. I have been able to increase the strength in my legs. Walking short distances poses no problems anymore. My balance is just as good as it was 30 years ago. A couple of years back, my grandsons were helping me put some boxes in the attic. I was up there with them in the way. As I stepped to the side to give them more room, I missed the decking I was moving for... Think you can see where this is going? Wrong! Having played Tai Chi for a couple of years by then, I knew I was in trouble and what I had to do. I shifted my weight immediately back to my stable foot and lifted my misguided foot before it went through the sheetrock ceiling. My foot did slightly hit the sheetrock leaving a thin crack which is still there today as a reminder to stay out of the attic.

In 2011, I developed pneumonia and two pulmonary embolisms in my lungs putting me in the hospital. I

believe that my experience and practice of deep-breathing exercises learned in my Tai Chi classes shortened my stay with a quick road to recovery.

**“I feel that Tai Chi has changed the way I look at life.”**

I still maintain a fairly high energy level allowing me to continue working in my yard when the weather permits and continue doing many of the things that I have enjoyed over the past half century. I feel that Tai Chi has changed the way I look at life. Through the exercise, I’ve learned that those with disabilities can adapt their lifestyle and still continue fulfilling their dreams.

If you do decide to try playing Tai Chi, be sure to check out your instructor. There are many out there but not all are proficient in Tai Chi. If you learn from a Master or Sifu you should be in good hands.

I still practice Tai Chi as often as I can, anywhere from 5 - 45 minutes at least 4-5 days a week.

A couple of years ago, I was asked to teach Tai Chi to our special needs Sunday school class. I felt that this was an opportunity to expand the art of Tai Chi in a different direction. I prepared a modified version of the 8-Step form for the class which proved to be a great success. I did have some challenges in that two of the students had difficulty in standing for any length of time, but we worked around that by taking breaks during the 1-hour class.

Watching these kids working at something they had never done before and achieve success was very rewarding. I felt that by modifying the form to a seated position, I would be able to reach many more students. This started me on a yearlong journey to write the “Seated T’ai Chi – Yang Style T’ai Chi Seated Workbook”. The workbook is based on the book “Tai Chi in a Chair” by Cynthia Quarta. With her permission, I was able to use some of her material as a base for the book which I dedicated to these special needs children.

I currently teach a seated Tai Chi class in a 55+ community here in The Woodlands, Texas and continue to assist my Sifu as an Instructor.

# Tai Chi Exercise

## SAMPLES

*Editor's Note: The following are two exercises from Wilson McCoy's Tai Chi workbook. If you are interested in additional information or ordering the workbook, please send Wilson an email at [hwmac43@gmail.com](mailto:hwmac43@gmail.com). All profits will go to The Woodlands United Methodist Church Special Needs program.*

### Repulse the Monkey

**Benefits -** Repetition of this movement will bring a considerable amount of energy to your hands and will bring your body into balance.

**Posture -** Begin by sitting with your back against the back of the chair. Legs should be shoulder-width apart, feet flat on the floor. Tuck your hips under slightly and curve your shoulders inward without hunching. Hold your head lightly on your neck as though it were suspended by a string from the ceiling.

**Visualization -** Imagine the electric currents passing between your hands as you pass one over the other.

1. Hold your left hand at face level with the palm facing upward.
2. Breathe in as you swing your right arm back, following the motion with your eyes by turning your head to look over your shoulder.
3. Now, as you breathe out, sweep your arm forward and over your shoulder so that your right hand will pass over your left about 2 to 3 inches above it.
4. Bring your right hand past your left hand facing slightly forward, fingers curled a bit.
5. Breathe in as you swing your left arm behind you turning your head to follow the motion and turn your right hand palm up.
6. As you breathe out, bring the left hand over the right (palms will be facing) without touching your hands together.
7. Slide the left hand forward palm slightly raised, fingers curled.

**Repetitions -** Seven on each side.



# Tai Chi Exercise

## SAMPLES



### Hands Waving in Clouds

**Benefits** – Strengthens shoulder and upper arm muscles and trims the waist.

**Posture** – Begin by sitting with your back against the back of the chair. Legs should be shoulder-width apart, feet flat on the floor. Tuck your hips under slightly and curve your shoulders inward without hunching. Hold your head lightly on your neck as though it were suspended by a string from the ceiling.

**Visualization** – Imagine that you are brushing puffs of clouds from in front of your face, chest and abdomen.

1. Begin with your left hand at eye level facing in and your right hand facing out at the lowest part of your abdomen.
2. Twist from your waist to the left, left hand held horizontally in front of your face. The right hand travels with the movement of the trunk leading with the inside of the wrist. Fingers should not be stiff and should be held apart so that you can look between your fingers. By allowing the muscles around your waist to relax you will be able to turn much further to each side.
3. Sweep back and forth, changing which hand is on top each time and switching the direction in which they are facing. The important thing to remember is that the movement is gentle and loose, arms sweeping gracefully from side to side.

**Repetitions** – Fourteen waves sweeping from side to side.

# Top 10 Tips For Managing An AS Flare

*Editor's Note: The following story was originally published in the Autumn 2013 issue of "AS News", a quarterly news magazine from NASS - the National Ankylosing Spondylitis Society, which is based in the United Kingdom (UK). Used with permission via a partnership with the Ankylosing Spondylitis International Federation (ASIF). Some minor edits for language and layout purposes were done.*

**About the writers: We are two Senior Physiotherapists (Brisa France and Ingrid Hill) working at the RNHRD in Bath. We have devised these top tips for managing an AS flare from our experiences of working with people with AS over the last 15 years.**

## 1 Understand your Condition

Educating yourself about AS empowers you to manage your condition more effectively.

Get good information and always ask questions at your appointments.

Write down the information you are given and keep it in a safe place so you can refer to it when needed.

Listen to your body and keep a mental note of how your AS changes, what helps and what seems to make it worse.

AS seems to have times of flare and episodes when it is more manageable or settled.

A flare can include pain, stiffness, and fatigue. Understanding all these features can help you to manage them.

**Pain** can be due to:

- Active inflammation in the tissues around the joints and tendons. This can be a very intense / raw type of pain.
- Shortening / tightening of muscles or tendons around inflamed areas. This can lead to a dull, achy type of pain.
- Protective muscle spasms pulling on inflamed sites. This pain can be intense and sharp.

**Stiffness** can be due to:

- Joints fusing or formation of bony bridges restricting movement.
- Muscles and tendons shortening and tightening, as part of the inflammation and healing cycle.

**Fatigue** can be due to:

- The inflammation and healing cycle using energy.
- Muscle spasms as a response to pain using energy.
- Poor quality sleep due to pain.

- Loss of deep sleep so energy levels are not adequately replenished.
- Stress from living with a chronic inflammatory condition.

## 2 Medication

You need the help of medicine to live with a chronic, inflammatory, and painful condition and to help deal with a flare. These include anti-inflammatories and painkillers.

We advise you take your medication, especially painkillers, as soon as you wake up and realize that you're having a flare.

The whole procedure of getting out of bed can be painful – so get help from your medication as soon as possible.

Keep an emergency pack of your medication, water, and a snack next to your bed. Remember it takes 20 minutes for your medication to start to work.

It's important to know the maximum dosage you can take in 24 hours for all your medications. It is easy to lose track of the number of doses taken, especially if you are feeling "muzzyheaded" and sleep-deprived.

Remember to replace your emergency pack of medicine for the next time it is needed.

## 3 Breathing Techniques

During the 20 minutes that you are waiting for your medication to work, the best and most effective thing to do to alleviate the flare symptoms is to BREATHE.

Research shows that just three good diaphragmatic breaths correctly learned when you are not experiencing a flare can greatly reduce pain levels by:

- Relaxing muscles.

- Controlling feelings of panic.
- Lowering your stress hormone levels.
- Giving you a feeling of being in control.
- Slowing your breathing techniques avoids the fast panicky upper chest breathing associated with flares and will help to flood your system with oxygen and nutrients which in turn will help to break the build-up of pain resulting in a constant cycle of pain.

## 4 Mind/Body Link

Never underestimate the strong relationship between your mind and body.

Your head will always influence your pain and conversely your pain will always affect your head and mind. Your pain signals are received in your brain and that is what controls your response.

So:

- **PLAN** a strategy where you make sure that you are in control of your AS and not the other way around. Your aim at this stage is to not allow the pain to build up to a level where it takes over your life; this is what is known as the cycle of pain.
- During a flare people can sometimes feel panicky, tearful and out of control. AS feeds off this stress.
- Acceptance. It is useful and helpful to think about your condition at this time, accept that you have it and then find a way to make it part of who you are but not what defines you.

## 5 Gentle Stretches in Bed

Whilst you are waiting in bed for your medication to take effect, don't forget that your bed is a soft, safe and gentle environment.

Your spine, joints and muscles are feeling warm and unaffected by the pull of gravity.

The worst thing to do is to keep still, even though it is the one thing that you most want to do. The key word here is GENTLE, a few simple stretches that you know well without aggravating your pain.

## 6 Get Out of Bed

Wait for the painkillers/medication to take effect before getting out of bed.

If you know it is going to be painful getting out of bed, then:

- Try to move in stages so you do not pull on muscles that are already in spasm.
- Move on the out breath - do not hold your breath while bracing yourself.
- Let your body adjust to each position before moving to the next one.

## 7 Shower/Bath

Warm water helps to relax tight muscles and release the stiffness in joints. It is also pain relieving.

You may find the jet of warm water from a power shower helps to soothe sore areas, like a massaging effect.

Soaking in a bath can also be soothing – if you can get in and out safely without causing more pain.

## 8 Stretches and Movement

The important thing to remember is that you won't hurt yourself if you have been taught the correct stretches by your physio.

Gently stretch the areas that stiffen up and tighten up. It is one of the main strategies for limiting the duration and intensity of your flare.

Try to go out for a short walk; natural daylight helps to lift the mood by releasing endorphins which in turn help you to cope with your pain.

## 9 Pain Relieving Techniques

During a flare it is useful to sit quietly and take stock of the situation. Then try some of these recommendations in combination with your medication.

**Hot bath /shower:** A combination of Epsom salts and/or your favorite aromatherapy oils can relax and help to lift your mood.

**Tens machine/pain pen:** Learn the correct way to use them, the pulsed program of impulses is better.

Learn **acupressure points** and then use them on yourself.

Learn **relaxation and or meditation** techniques.

## 10 Educating Family, Friends, and Colleagues

It is best to explain your condition when you are feeling well.

There is nothing worse than having to explain AS when you are feeling unwell, miserable, grumpy and tearful.

People close to you can become anxious and worried when they see you in pain; it can help to reassure them if they understand your condition.

Some people have a code word for a bad AS day so the whole family can understand how they are feeling, and this helps to decrease tension for everyone.

**Finally** If your flares increase in number or intensity, seek advice from your rheumatology team or GP as your medication or its dosage might need changing.

**DO NOT SUFFER IN SILENCE.** There is help out there.

Is advancing the goal of a world without the pain and disability of spondylitis more important to you than, say, .....potato salad?



*“Basically I’m just making potato salad. I haven’t decided what kind yet. It might not be that good. It’s my first potato salad.”*

With those words, an enterprising young man named Zack “Danger” Brown took to the online crowdfunding platform Kickstarter and announced to the world his goal of raising \$10 to buy the ingredients for this appetizing summer picnic staple.

And the pledges started pouring in.

Donors and admirers alike took to social media to spread the word and make this unorthodox but endearingly high-carb endeavor the hot potato of the Internet.

Mainstream media outlets covered the story with relish and Zack was soon the darling of the morning talk show circuit. Potato farmers everywhere rejoiced.

And the questions flowed: “Mayonnaise or vinegar?” “Mustard or no mustard?” “Gold potatoes or red?” “Cold, room temperature or warm?” “Eggs?” “Will there be a vegan version?”

Zack was flooded with Facebook friend requests, the Twittiverse exploded with tater-mania, Pinterest pages devoted to this trending starchy delicacy multiplied.

Today, *YouTubers* searching “Potato Salad Kickstarter” will unearth over 6,800 results, while the more encompassing Google search returns more than half a million hits.

A few weeks later, almost 7,000 donors had forked over more than \$55,000, making this one of the most successful fundraising campaigns in recent memory.

Good for Zack. It was a brilliant mash of performance art and marketing genius, however unintended. From what I've read, he never even expected to hit his \$10 goal but will now join the ranks of the accidental phenoms who have come before — Steve Hartman, who gave us the pool noodle; Gary Dahl, father of the Pet Rock; and Richard James who dropped a tension spring on the floor and thus the Slinky was born.

As amusing as the situation is, there are also many people who find that the campaign's stunning success leaves a bitter aftertaste. As a hard-boiled, seasoned fundraiser, I can't afford to be thin-skinned but I can't help feeling an odd combination of resentment/envy when I see how effortlessly this gentleman raised money for a lark knowing how hard it is to do the same for a true and present need.

When so many worthy charities find it to be an uphill battle to raise the funds needed, it's difficult to reconcile the fact that people will flock to give money to a cause célèbre rather than an actual cause.

To put it in perspective, SAA's Spring Appeal raised just over \$30,000 to fund the programs and services that will potentially benefit the **2.7 million** people living with spondylitis in the US. Contrast that to over \$55,000 raised in a couple of weeks to help one man make a side dish.

So, while it's a fun thing – it's still a bit disheartening to see that people will come together for potato salad, but often won't for the greater good.

But, you know what? I'm more than happy to learn from Zack. And I actually like potato salad. So, if you'd like the SAA staff to have a potato salad-themed potluck, I'm sure I can get my co-workers to go along. And, if the campaign has even a fraction of the success Zack has achieved, we'll provide pictures in a future issue. So, for \$5, \$10, \$20, \$100 or whatever you can afford, we'll peel, dice, slice, season and garnish.

Rest assured, not a penny will be spent on potato salad; we'll cover *that* ourselves.

Your hard-earned dollars will go toward ushering in a world where spondylitis isn't the burden it is today. The spuds are on us.

Diann

*Diann Peterson*

Director of Annual Giving

*P.S. Right now, and through October 31<sup>st</sup>, every contribution you make to SAA will be matched dollar for dollar thanks to a generous \$25,000 Challenge Grant from the Jean & E. Floyd Kvamme Foundation. That's a lot of potatoes. This challenge is for a limited time only, so please give today. We're ready to start cooking!*

# OVERHEARD:

## An SAA Facebook Discussion On Exercise

A recent study published in *Arthritis Care and Research* \* on why many arthritis patients do not exercise found “lack of motivation and disbelief in the benefits of exercise on arthritis” to be the biggest reasons. This was a study with RA patients specifically, and so we wondered how our spondylitis community compares.



We posed this question to our Facebook community to get an idea.

“Do you exercise regularly? How often? If not, what is your biggest obstacle/reason why you don’t? And do you believe that regular exercise helps with pain and other symptoms?”

Below is a sampling of the responses we got.



**Jessica W.** “I exercise regularly. It helps me keep moving and decreases the amount of pain that I am in.”



**Mitchie V.** “Yoga and biking have helped my arthritis symptoms more than any medicine.”



**Samantha P.** “Exercise helps me so much from being stiff. The problem is sometimes my fatigue is so bad I just can’t get out the door to walk around the block.”



**Eileen D.** “Why don’t I exercise as much? BECAUSE IT HURTS!!!!!!”



**Janice B.** “Fatigue is my obstacle. In my head, I know it will help, but I’m just not motivated.”



**Fiona C.** “I just can’t. I hurt every day, I’m sore and fatigued. It’s hard enough getting in my 10,000 steps, if I do any physical exercise I end up in bed for a week!”



**Eric S.** “Sunday I could hardly move. Today I could walk and MAYBE lightly jog. It really depends on the day for me. I’ve done both low and high impact exercise, and actually they both can hurt depending. I do generally have more success with low impact, but it’s not a free ride.”



**Greg P.** “Exercise offers one of the few times I actually feel really good, it’s the before and after that gets ugly! Elliptical, weights, kickboxing (moderated as necessary) and my real treat, an adult tricycle! Some days, just showing up is a win.”



**Jamie M.** “I workout at least three times a week. It definitely helps—not only physically, but mentally, as well. There have been times that I physically couldn’t do it in the past, though.”



**Caroline O.** “Yes. 5 - 6 times/week. Exercise has made my pain level and stiffness so much better. It was very hard to start exercising after some months of inactivity when I had a lot of pain, but now I have to train (mostly cycling) to keep the pain on as low a level as possible. I do use medications, but I feel better when I exercise regularly.”



**Angel M.** “For me the daily pain is a deterrent. Even when I do some gentle work it will take my body days to recover.”



**Sabrina M.** “Exercise has rescued me from this disease! I do it 40 min on average every day. Sometimes I think I hurt too bad to try ... then I convince myself to do it anyways and I always feel better after.”



**Danielle W.** “I hurt myself sneezing so how in the he!! am I supposed to exercise?”



**Richard H.** “Yoga & spin. I’m a mess if I don’t do it. It’s not for everyone but it’s been a game changer for me. Sleep, activity, stress reduction and diet are my health pillars.”



**Melanie M.** “Pain and fatigue... exercise for me definitely decreases the pain but then it’s near impossible to exercise when you’re in extreme pain! It’s a difficult downwards spiral to get out of (pain = no exercise = more pain = no exercise = even more pain, etc). I’m there now - just walking to the bathroom is agony but I know I have to move if I want to get out of this pain!”



**Chris C.** “The people who are commenting about why they can’t exercise have a common theme...exercising correctly and doing the right types of movements, and with appropriate amounts of stress is difficult to dial in...It takes time. You should also consult with professionals who know what you are going through...I don’t know your pain, but mine has benefited by trial and error and finding the right balance...good luck!”



**Melissa E.** “It’s such a fine line between “this is an ok amount of exercise” and “oh crap, I overdid it and triggered a flare” that I am terrified.”



**Lynda D.** “I went to 5 rounds of PT. They couldn’t do anything with me. Nothing helped, and everything they tried would set off flares. I finally decided to just be grateful that I could take care of myself and my home. That was exercise, maybe mild, but some! The massage therapist working my muscles was exercise, so I was grateful for that. And now after years, I’m able to do some gardening and light bike riding. I used to feel really down by AS people that would say just get out there and “do it”. What??? .... Just do it and then have to dose up on high prednisone, be in massive pain, spend more time in bed than not?? I finally threw that model away. Gratefulness for small victories helped me!”



**Eva C.** “I go to a water exercise class 3 days a week. It is amazingly helpful. My motivation is that I hurt if I do not exercise.”





**Brinkley B.** “I am newly diagnosed, and have hardening in my SI joint but no fusion yet. I started an exercise regimen almost immediately in hopes of slowing its progression, 8 weeks later I’ve already gained 4cm of mobility in my back! It may not stop my disease, but by golly I feel 100 times better and will continue to exercise as long as I’m able. I will not let this disease win if I can help it!!”



**Marci B.** “I wouldn’t have a life worth living if I didn’t. I was fortunate to find a Tai Chi class held in a pool, which gave me a gentle beginning. I now do Tai Chi on land as well as in the pool and as I look back am amazed at the increase in my mobility. If it weren’t for the fact that this is my second time learning Tai Chi, I might not know how much it has helped. I had played Tai Chi for over 10 years when I quit, thinking it wasn’t helping all that much. Boy was I wrong! I had both hips replaced soon after I quit and felt miserable most of the time. After my surgery I found the pool Tai Chi class and am still working to improve my mobility AND doing other exercises for strengthening my back. I now know that the exercise works, now that I can compare how I felt with and without doing it. It isn’t a cure and doesn’t take all the pain away but I know it’s worth the struggle to get started and keep going.”



**Tricia C.** “I would love to exercise and love the way it makes me feel, but I’m so freakin’ tired all the time!”



**Carol E.** “I have Lupus, RA, Fibromyalgia, Ankylosing Spondylitis and Meniere’s disease...I had the mindset that I couldn’t exercise, until I finally decided these conditions were not holding me back. I started slowly with short walks and stretching which gradually turned into working out at the gym, yoga, walking, running. I’ve been running races since last year and am training for my first half marathon this year. I am medication free (6 months) and only see my Rheum once a year now! I definitely believe in the power of exercise, diet and learning all you can about the triggers of your conditions. I still have bad days and setbacks but I really feel worse when I’m not moving and active.”



**Fred P.** “I am fused completely in the neck area and hunched forward. I tire easily as if I were carrying a millstone around my neck. But I have been lifting light weights and walking for almost two years and it has helped immensely with pain and inflammation. Yes I have days when I am too tired to work out but they have become less and less. I feel better, have lost weight and have a bit more flexibility in my back (not neck area). Start slow and at a pace you feel comfortable with. You are probably not training to be Mr. or Ms. America or an Olympian. Btw- I am 60.”



\* *Arthritis Care and Research*,  
(Volume 64, page 488).

[http://www.johnshopkinshealthalerts.com/alerts/arthritis/Arthritis-Exercise\\_6459-1.html?ET=johnshopkins%3Ae105955%3A1986467a%3A&st=email&s=EAH\\_130401\\_001](http://www.johnshopkinshealthalerts.com/alerts/arthritis/Arthritis-Exercise_6459-1.html?ET=johnshopkins%3Ae105955%3A1986467a%3A&st=email&s=EAH_130401_001)

## Internet Rock Festival Features Over 70 NJ Artists Banding Together for BlowUpRadio.com's Annual Spondylitis Benefit - October 17 to 20

**BlowUpRadio.com, NJ internet radio station, presents *eighth annual benefit* for genetic arthritic disease research.**

BlowUpRadio.com, where NJ rock lives, once again brings together some of the best local indie musicians for the eighth annual Banding Together: A Benefit Webathon For The Spondylitis Association of America.

Ankylosing Spondylitis is a genetic arthritic condition that can cause inflammation and fusion in the vertebrae of the spine. To date, BlowUpRadio.com has raised thousands of dollars for the cause, and raised awareness of the genetic disease, which the Centers For Disease Control says over 2.7 million American adults have.

"This is a very personal benefit for me as my wife, Naomi, suffers from ankylosing spondylitis (AS).", says Lazlo, the founder of BlowUpRadio.com and the organizer of Banding Together, "I have seen the debilitating effects of this disease and the chronic pain and discomfort it causes. This benefit is the least I can do to help my wife, and over a million others who suffer from AS."

During the course of Banding Together, more than 70 bands, many from New Jersey's local music scene, will perform live on a two-stage virtual festival featured on BlowUpRadio.com and 40FootHoleStudio.com.

Listeners will be encouraged to donate money via a secure online section of the Spondylitis Association Of America's website.



Everybody donating during the webathon will receive a digital download of an exclusive collection of songs from many of the bands performing. A complete track listing will be available in early October on <http://www.BlowupRadio.com>

"I am very excited that this year in association with 40FootHoleStudio.com, we can have a virtual festival with two stages of continual live performances all weekend."

For more information on Banding Together, and to see the YouTube promotional video, go to <http://www.BlowupRadio.com>

**Want to get involved? Hold a fundraiser? Volunteer? Learn how at**

**[StopAS.org/Volunteer](http://StopAS.org/Volunteer)**

# Yoga & AS: A Love-Hate Relationship

by Richard Howard, Los Angeles Support Group Leader



20 years ago, I was out of medical options for my ankylosing spondylitis. It was before the biologics came out and I had life threatening consequences to the existing medicines. I needed a new plan.

At my bride's prompting, I reluctantly went into Lee Lones' 7:30pm yoga class at my gym. I went to the back corner of the already dark studio. I hated it. I loved hard, fast paced sports. I was still grieving over being told not to run or play rugby ever again.

Lying on the mat, I was reminded how inflexible I was with every stretch. Instead of spending 24 hours a day trying to make the disease invisible to me as well as the rest of the world, I was being forced to examine every detail of limitation. What a nightmare...But what a blessing.

Over the years, I've learned to modify any pose so that no matter how bad I feel before yoga, I'm always improved walking out. I still have reduced range of motion, but that's not the point. Exploring the edges is the point and "spondys" have the advantage because the boundaries are easy to find.

I'm more flexible on so many levels. My practice positively influences my stress level, sleep, breath, diet, strength, attitude and relationships. Yoga has been my "weekly injection" ever since that first class and I never skip a dose.

I went through teacher training so that I could help modify a yoga practice for my "spondy-friends" with different physical challenges. Now, when someone with spondyloarthritis asks me a yoga question, I can offer them a free private yoga class. "Come to the support group meeting next month and I'll give you private yoga instruction before or after the meeting. I won't charge, just make a donation -of any amount- to the SAA."

Like yoga, the SAA makes spondylitis visible. Once a month, for two hours, I'm in the room with people that "get it". There is so much experience in the room. When someone asks a question, chances are at least four people in the room have experience with that same issue. "Who here has had severe fatigue?" Every hand went up. For a couple of hours you feel normal. You feel empowered by the tips people offer. Walking back to my car after a meeting, one person said, "I got more information about spondylitis in an hour of that meeting than in all my doctor appointments put together, and I have had a lot of doctor appointments!"

Our group likes to have speakers, we have had 11 speakers in the past 22 meetings, everything from rheumatologists, psychologists, eastern medicine practitioners, insurance professionals, workers comp experts, researchers, yoga instructors, etc. After a meeting, one renowned rheumatologist told me that these meetings are more valuable than a doctor's appointment. Like yoga, knowledge and modification has been the cornerstone to my managing spondylitis.

In yoga terminology, the support group is a 'Kula' (coolah), which means, "a community you participate in with likeminded individuals." Some people attend regularly, some sporadically when there is an interesting speaker or when they are going through a particularly tough time. Some people come once, and I think they just need to see and hear what it's like to live with spondylitis for 5 years, 10, 20... decades. We have all ages, ethnicities, severity and duration of spondylitis. No two people are experiencing spondylitis exactly alike. But, by the heads nodding during the meetings, it's clear we all speak the same language. This is something you can't get anywhere else.

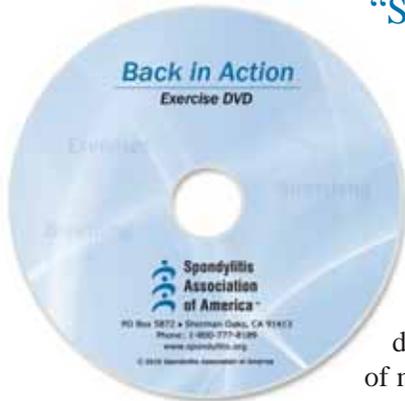
## Learn More About SAA Support Groups

To see a listing of all SAA Sponsored Support Groups and meeting times go to:

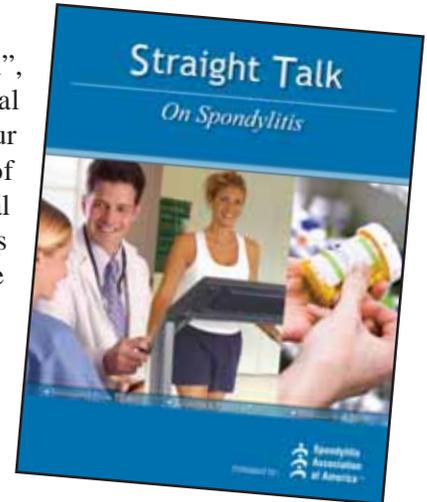
[www.StopAS.org/groups](http://www.StopAS.org/groups)

# GET BACK IN ACTION!

SAA can help you get moving with our Exercise DVD and our “Straight Talk On Spondylitis” book, which has sample exercises and an exercise poster!



In our exercise DVD, “Back in Action”, Donna Everix, PT, MA, expert physical therapist in spondylitis, gently guides four people with varying degrees of spondyloarthritis through a series of special stretching and strengthening exercises designed to help them retain strength and range of motion. Length is approximately 50 minutes.



Our 63 page book on spondylitis. Internationally recognized, this newly expanded and updated book is the most comprehensive resource available to help people understand and manage spondylitis and related diseases. An exercise program and illustrated wall poster are included with the book. Softcover 8.5x11

*Visit us at [StopAS.org/store](http://StopAS.org/store) or call 1-800-777-8189 to purchase  
Both can be bought together for a special price*

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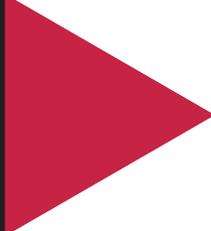
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