Your Stories: A Rough-Hewn Kind of Beauty

Does the microbiome cause ankylosing spondylitis?

Your Stories: A Rough-Hewn Kind of Beauty

Your Stories: A Story About Eggs
Dear Friends,

Having just returned from our weeklong participation in the American College of Rheumatology Scientific Meetings held in Chicago this year, there is much to report to you. This is a well attended meeting with roughly 16,000 registered individuals, including worldwide rheumatologists and associated healthcare professionals. The meeting consists of scientific poster presentations of new findings; general sessions with several thousand participants; and “Meet the Professor” workshops that present ongoing advancements in basic research and in clinical practice. In addition, new approaches in disease management are presented, newly approved guidelines are announced and upcoming therapies are presented to attendees.

With regard to research funding, as many of you may be aware, this past year has been one of the worst in terms of funding new studies, especially in rheumatology. In the past year, 90% of research grant proposals were turned down. Consequently, SAA has refocused its efforts this past year on supporting researchers who have demonstrated a track record in serving our constituents. Earlier this year, SAA provided funding to Dr. Michael Weisman and his team at Cedars-Sinai Medical Center in LA to support one year of patient care associated with the TASC longitudinal study in which many of you have been volunteer participants for the past decade. Thank you. In addition, one of the highlights of the Spondyloarthritis (SpA) Study Group Scientific meeting, which is attended each year by the thought leaders in SpA, was the presentation of the first SAA-Jane Bruckel Young Investigator Award. This year’s award went to Judith A. Smith MD, PhD. You can read more about Dr. Smith on page eleven.

Yet another highlight of the meeting for those committed to Spondyloarthritis was a journalist training workshop hosted by SAA. It was with great pleasure that we hosted this training session in SpA for journalists across the globe, which also was streamed live internationally with simultaneous translations in multiple languages including Mandarin and Spanish.

There is much more to do, but we are confident that with your ongoing support, we will conquer this group of diseases that impacts so many lives in the US and beyond.

Thank you for your support. From all of us here at SAA, please accept our warmest personal regards and fond wishes for the New Year.

Sincerely,

Laurie M. Savage, Executive Director, SAA
A Storm For Mick Mars & SAA
On behalf of my 13-year-old daughter, Storm Diehl, I am sending in two checks to the SAA.

She raised money selling bracelets and ribbons that she made, but we couldn’t have done it without SAA’s help. She raised a total of $270.00.

Storm is very passionate about this cause. Her idol, [Mötley Crüe guitarist and AS patient] Mick Mars is the reason she wanted to help raise awareness.

We couldn’t be more proud of our young daughter.

Sincerely,

AMY DIEHL

Editor’s Note: Thank you so much for your efforts, Storm. You did an amazing job raising awareness and we thank you for your support. Without people like you, SAA would not be the organization it is today.

Blogging For Support
I hope that this letter finds you well. I would like to thank you and everyone at the Spondylitis Association of America for all your hard work.

I, along with others, do our best to raise funds for this wonderful organization, but we also do a lot to raise awareness of Ankylosing Spondylitis. I have had the honor and privilege to meet some wonderful people due to this disease - that being one of the many blessings that helped me “find myself”, which is something I wasn’t able to say when I was initially diagnosed.

I belong to an awesome group of people who are from many parts of the world and we blog online on how AS affects us personally. The reason for my letter is to request that there be a blog section placed on spondylitis.org so that people with spondylitis could find someone they can connect with. Having someone who walks not only in your shoes but who can walk beside you is key. I would not have been able to make it these past few years without the support of my fellow ASers.

Thank you and sincerely,

CHERYL HOPPER aka Cookie

PS. The blogger group website I belong to is masqueradeofwords.wordpress.com

Editor’s Note: Thanks much for your letter, Cheryl, and we are glad you found a way to share stories and connect with others regarding spondylitis. SAA has actually launched a new program called, “SAA Connections” where people can seek support from fellow ASers, share their stories, chat online and more. We have discussed adding a blogging area for members, so hopefully we can do that in the future. Visit us at spondylitis.org/connect.
Physicians and scientists relentlessly search for clues as to what causes or affects a disease. Is it more common in women or in men? Is it more common in certain geographic areas? Is there any obvious environmental trigger such as an infection? Such clues can speak volumes about pathogenesis, a fancy medical term for causation. And understanding causation holds promise for finding improved therapy.
FEW CLUES IN MEDICINE are as dramatic as the relationship between HLA B27 and the development of ankylosing spondylitis. HLA B27 is a genetic trait that one is born with, much as your blood type, A, B, AB, or O, is determined at birth. While there are only four blood types, there are hundreds of HLA types. About one person in every fourteen in the US has the B27 type. Nearly forty years ago, a group in Los Angeles and a group in London discovered that the B27 type increased the odds of developing ankylosing spondylitis by about 100 fold. This is a phenomenal clue because most genetic factors increase the risk of developing a complex disease less than two fold. We now know a great deal about the HLA B27 molecule. We think that we know its function which is to help some cells in the immune system communicate or present antigen to a type of white blood cell called a T lymphocyte. And we think that white blood cells are the basis for a variety of immune mediated diseases including ankylosing spondylitis. We know that there are at least 65 closely related variants of HLA B27 and all but two of these increase the risk to develop ankylosing spondylitis. We know that rats that are genetically manipulated to express HLA B27 along with an important cofactor called beta 2 microglobulin spontaneously develop spinal arthritis that mimics many aspects of ankylosing spondylitis. But with all these tools to study HLA B27, we still have not figured out why it increases the likelihood to develop ankylosing spondylitis so dramatically.

Since conventional approaches to understand the relationship between ankylosing spondylitis and B27 have failed, the time seems ripe for a more novel theory. Enter the concept of the microbiome.

The term, microbiome, has been attributed to the Nobel laureate, Joshua Lederberg. It refers to the microbial world that lives in us and on us usually to mutual benefit. For example, most of the vitamin K which we need to make clotting factors is provided by bacteria in our gut. It is estimated that our bodies contain ten trillion cells. But we are host to 100 trillion bacterial cells. And for every RNA message that one of our cells is producing, the bacteria within us are producing 100 more. Surely these bacteria are important to our health.

Recent studies in mice have revealed that bacteria profoundly shape our immune system. It is possible to raise a mouse or a rat in a sterile environment such that bacteria never have a chance to grow inside the intestine. Without these bacteria, the immune system never develops. If the HLA B27 positive rat is raised in this type of “germ free” environment, it develops very little arthritis. Mouse models of various diseases like asthma and colitis can be effectively treated just by feeding mice specific bacteria, and sometimes even just feeding products from those bacteria. The B27 positive rat develops reduced arthritis if it receives antibiotics. And this remission is sustained if it swallows a specific strain of lactobacillus but not if it swallows a different strain. Lactobacilli are ingested by millions daily in the form of yogurt. And the strain of lactobacillus used to treat the B27 positive rat can be purchased in a health food store or in specific yogurts.

Ankylosing spondylitis clearly is a disease caused by the immune system. For a century we have known that certain bacteria can trigger a reactive arthritis, especially in HLA B27 positive individuals. Now we know that intestinal bacteria shape our immune system. Because all HLA molecules affect the immune response, it is highly likely that HLA B27 helps to determine which bacteria are in our microbiome and that in turn affects the likelihood that we will develop ankylosing spondylitis.

“Ankylosing spondylitis clearly is a disease caused by the immune system...
Now we know that intestinal bacteria shape our immune system.”

Before you rush out to buy yogurt or lactobacillus, there are a number of holes to fill in this hypothesis. First, if HLA B27 does change the bacteria that live within us, we need to define this change. But this is no simple task. A major reason why we are just now learning about the microbiome is that most of the bacteria in the gut do not grow on a culture plate. They are very fastidious, meaning that they only grow when they have specific conditions within the bowel. New molecular techniques have allowed scientists to study the bacteria without culture. This is done similarly to the way a forensic pathologist would attempt to identify a person from a single hair or a drop of blood. Second, the easiest bacteria to study are those that are present in feces, but the bacteria in the appendix, or the cecum, or the ascending colon might be the critical ones to study. Third, people are not mice and while we can extrapolate a great deal from the immune system of mice to the immune system of man, there are clearly differences. And finally, very closely related bacteria might have different effects. In the rat studies, one strain of lactobacillus worked in
the B27 rats, but lactobacillus can worsen another rodent model of arthritis.

Psoriatic arthritis and inflammatory bowel disease each have features that overlap with ankylosing spondylitis and many experts believe that each is triggered by a reaction to bacteria.

So if it is true that HLA B27 shapes the microbiome and the microbiome shapes the immune response and thus leads to ankylosing spondylitis, how can we test this hypothesis? Animal studies will be invaluable although diseases in mice and rats resemble human disease but never exactly duplicate it. We could design a study in which a probiotic like a specific lactobacillus or a diet was used to change the microbiome and thus prevent ankylosing spondylitis. The challenge with such a study is to determine when ankylosing spondylitis begins. The onset of AS is often so insidious that it might be impossible to know which subjects were truly prevented from developing inflammatory low back pain. The uveitis or eye inflammation associated with ankylosing spondylitis is much easier to date in terms of onset because the eye typically becomes affected over a few days and new redness, pain, and light sensitivity develop. Trying to prevent uveitis attacks in patients with AS by using a diet or probiotic might be an excellent surrogate for trying to prevent the spinal arthritis.

Even in the year 2011 when we have achieved so much scientifically, we still have many unknowns and many frontiers. The microbiome is a vast frontier about which very little is known. Alteration of the microbiome potentially could be used to treat or prevent many diseases caused by the immune system including ankylosing spondylitis.
Nearly everyone who has read about ankylosing spondylitis knows it is heavily genetically determined. We also know that HLA-B27, discovered nearly 40 years ago, is the primary culprit. However, thanks to all of you who have taken the time to participate in research, the following chart shows more genes associated with the susceptibility of AS - and all of them have been discovered in the last four years.

In the future, these newly discovered genes could lead to improved diagnostic tests as well as new treatments. None of this would have been possible without those participating in studies beginning in 1998 with the NASC family study up to the current TASC study (Triple “A” Spondylitis Consortium Genetic Study). We’d like to thank John D. Reveille, MD, for continuing to help drive genetic research of spondylitis.

<table>
<thead>
<tr>
<th>Gene</th>
<th>Chromosome</th>
<th>Function</th>
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<tbody>
<tr>
<td>IL23R</td>
<td>1p31.3</td>
<td>Interleukin 23-Receptor-Key regulator of the TH17 response</td>
</tr>
<tr>
<td>RUNX3</td>
<td>1p36</td>
<td>Runt-Related Transcription Factor 3 encodes a transcription factor involved in CD8 lymphocyte differentiation</td>
</tr>
<tr>
<td>KIF21B</td>
<td>1q32</td>
<td>Kinesin Family Member 21B, a member of a family of plus end directed kinesin motor proteins of unclear relevance to IBD.</td>
</tr>
<tr>
<td>IL1R2</td>
<td>2q12</td>
<td>Interleukin 1 Receptor 2 gene encodes a protein that acts as a decoy receptor, interfering with the binding of IL-1 to IL-1R1.</td>
</tr>
<tr>
<td>ANTXR2</td>
<td>4q21</td>
<td>Anthrax receptor 2 (capillary morphogenesis protein-2-CMP2), binds to collagen IV and laminin, suggesting that it may be involved in extracellular matrix adhesion.</td>
</tr>
<tr>
<td>PTGER4</td>
<td>5p13.1</td>
<td>Prostaglandin E Receptor 4, stimulates DC production of IL-23, and in turn Th17 expansion</td>
</tr>
<tr>
<td>ERAP1</td>
<td>5q15</td>
<td>Endoplasmic reticulum aminopeptidase 1-acts as a molecular ruler in trimming peptides for loading onto MHC class I molecules, facilitating antigen presentation</td>
</tr>
<tr>
<td>IL12B</td>
<td>5q31</td>
<td>Interleukin 12-Beta, encodes the IL12p40 protein, a component of both IL-12 and IL-23</td>
</tr>
<tr>
<td>CDKAL1</td>
<td>6p22.3</td>
<td>CDK5 Regulatory Subunit-Associated Protein 1-Like 1 gene, associated with type I diabetes, immunologic function unknown</td>
</tr>
<tr>
<td>CARD9</td>
<td>9q34.3</td>
<td>Caspase recruitment domain-containing Protein 9, participates in apoptosis signaling, induce nuclear factor kappa-B (NFkB)</td>
</tr>
<tr>
<td>TNFRS1/ LTBR</td>
<td>12p13.2</td>
<td>Tumor Necrosis Factor Receptor Superfamily, Member 1A associates with the MADD protein through a death domain-death domain interaction, providing a physical link between TNFR1 and induction of mitogen-activated protein kinase activation and arachidonic acid release.</td>
</tr>
<tr>
<td>TRADD</td>
<td>16q22</td>
<td>Tumor Necrosis Factor Receptor Type 1-Associated Death Domain is a negative regulator of Ifng-induced Stat1 DNA binding, activation, and function.</td>
</tr>
<tr>
<td>STAT3</td>
<td>17q21.31</td>
<td>Signal Transducer and Activator of Transcription 3 is a transcription regulator constitutively activated in intestinal cells of patients with Crohn’s disease, key in regulating TH17 responses.</td>
</tr>
</tbody>
</table>

~John D. Reveille, MD 2011.
Some months ago, a phone conversation with my BlogHer colleague Rita Arens turned toward my experience of having ankylosing spondylitis, an arthritic condition that froze my spine over the course of 30 years, first into a ramrod pole and now into a shepherd’s crook. With her encouragement, I jabbered on about how, along the way, I’ve loved and lost, borne and raised two children, managed a career and had bi-lateral hip replacements - two surgeries - a week apart, followed by single doses of radiation. Then Rita suggested that my story would be a good addition to the “Own Your Beauty” series.

That shut me up.

I don’t write about AS. I haven’t really had the words. And talk about it in the context of a conversation about beauty? Beauty has been a vexed notion for me all my life. Being born into a striving black family meant focusing on achievement, not beauty. Coming of age in the 1970s, of course, I was black and proud, owned a copy of Our Bodies, Ourselves, and read Essence magazine cover to cover. But I didn’t have much of the socialization into beauty culture that it’s assumed American women go through. My friends and most of my female relatives don’t wear make-up. They like nice clothes but don’t obsess about them, and it’s only with the arrival of my daughter’s generation that I’ve heard any of them squeal about a pair of shoes.

Ankylosing spondylitis robbed me of the one thing I’d always considered foundational to being beautiful: erect posture. When I was at my most bitter and self-pitying, it seemed to me that AS made a proud black woman bend like a swaybacked Georgia mule. When the condition started to remold my body during my late 20s and 30s, I started to feel walled off from other women. I gradually lost the physical ability to do simple things women do to make myself look presentable and professional - much less attractive.

I once had a friendly relationship with my body. As a teenager, I had worked it into a fairly athletic condition using yoga, calisthenics, and weights. I loved the way my legs pumped and my lungs filled when I rode a bike. I loved the way my body flowed, bumped and swiveled to music. And yes, there was a time that I enjoyed the way it looked in a bathing suit and let me slice and kick my way across a swimming pool. In other words, I liked my body as much for what I could make it do as for the way it looked. Then ankylosing spondylitis started locking my vertebrae, sapping my
energy and turning me into a woman who hunched like the hated teacher in that 90’s cartoon, “Recess” and moved (to my mind) like Lon Chaney in the Hunchback of Notre Dame. I felt betrayed. Like Job, I wanted God to tell me what I had done to deserve this.

It would take a few years before I got off my high horse and acknowledged that there was nothing special about me that should make me exempt from illness or disability. Why me? Why not me? And by now, I knew plenty of people who would have been happy to have had the 29 years I’d had of being able-bodied. I also knew that there was plenty that this body could still do, if I treated it right. And so, I sought my body’s forgiveness, and we’ve reached a kind of friendship again where I do my best to keep it fed, exercised, medicated and rested, and it does its best to keep me as upright as it can ...

So I can look at my body in a mirror with respect, and even care, but beauty? What does that mean for me, anyway? Around the time I turned 50, I joined Facebook. Over the next couple of years, I scanned and posted just about every picture I found of myself, from toddlerhood through middle age. Part of me wanted to tell the world that I hadn’t always looked like this. When old school friends posted their own pictures of me from college, I snapped them up for my profile. Part of me wanted my children to see what Mommy used to look like.

What amused and surprised me was the number of male friends - some of whom had been objects of my silent affection in college - who commented on how beautiful I was in those old photos. Of course, they never gave me a second glance when I actually looked liked that. A young woman grows prettier in the nostalgic mind of a middle-aged man, I learned.

My body had become so alien to me for so long that I had ceased to think of it as anything to which one could attach beauty or ugliness - certainly nothing like sexuality. It’s not that I ceased to be a sexual being, that’s just part of being human. It’s that I had to find a new way to think of myself as a sexual being, since my body didn’t function the way it once had. In those days, my body was a conveyance for my senses, and a means of doing the work I had to do to get my children grown. It was a thing apart from me.

I knew of others who had been forced to make similar adjustments. As a young woman, I worked for a comprehensive cancer center as a lay counselor and newsletter editor. In the course of that job, I learned a bit about sexuality and body image counseling for cancer patients. I worked with people coping with the loss of breasts, testicles, limbs, or the sudden presence of colostomy bags.

However, psychosocial support for ankylosing spondylitis patients is limited, because it is a relatively rare condition. I was diagnosed in 1986, and I didn’t meet another woman with the condition until 2003. I still haven’t met another woman who has dealt with AS during a pregnancy. There are now some online support groups, but the one thing I learned is that everyone’s experience with this condition is completely different.

I told a friend that I later realized that part of what I was doing was trying to see the changes in my own body over time - to make me real to me. For so long, I had felt like this able-bodied woman trapped inside this alien shell that looked like me. Seeing the photos over the years helped me absorb the truth that the body I had once had, the one that pressed its strength against the world, danced in moonlight, and rose with the dawn to suckle my first born - that body had been transformed. What has replaced it may not be as graceful on the outside, but it has its own rough-hewn appeal. It endures. It holds off the ravages of time so I can love a bit longer and learn a bit more. And it still lets me dance.


“Ankylosing spondylitis robbed me of the one thing I’d always considered foundational to being beautiful: erect posture.”

www.spondylitis.org
Today, my children are grown, my career is in a satisfying place and I’ve grieved enough to know that life is precious and meant to be savored, even when it doesn’t deal you the cards you expected or wanted. So I suppose, in that sense, I can own up to a kind of beauty...

...Yes, I can.

Tell Us Your Story

Check out other member stories online at:

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

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

SAA’s 2010 Recipient of the Young Investigator Award

SAA has established an award called the SAA-Jane Bruckel Young Investigator Award that is given annually to a young researcher who presents the best abstract on spondyloarthritis at the annual meeting of the American College of Rheumatology (ACR). This year at the 2011 ACR meeting, the $10,000 award to support spondylitis research went to Judith Smith, MD, PhD, who presented the winning abstract at the 2010 meeting.

About Dr. Smith
Dr. Judith Anne Smith graduated summa cum laude from Yale University. She then completed her MD/PhD program via the NIH Medical Scientist Training Program at the University of Chicago. Her graduate work in Immunology was performed under the guidance of Dr. Jeffrey Bluestone. After completing her medical degree, she did her Pediatrics residency and Pediatric Rheumatology fellowship training at Cincinnati Children’s Hospital. Her fellowship training under Dr. Robert Colbert inspired her to pursue research in the pathogenesis of ankylosing spondylitis and related conditions. She joined the faculty as an Assistant Professor in Pediatrics at the University of Wisconsin in Madison. There she continues to care for pediatric patients in the Rheumatology clinic and leads an active research program. Dr. Smith’s research goal remains to elucidate the fundamental processes that drive the evolution of ankylosing spondylitis in hopes of ultimately leading to more rational therapeutic development.

About Dr. Smith’s Winning Study Presented at the 2010 ACR Meeting:
The macrophage is an important cell in the inflammatory response. The cells in the immune system produce cytokines such as TNF when they are activated. Inhibition of these cytokines can be an effective therapeutic strategy.

Judith Smith and her colleagues at the University of Wisconsin showed that compared to healthy controls, macrophages from patients with ankylosing spondylitis make more cytokines when stimulated with a bacterial product. The cytokine IL-23 was especially increased. Pharmaceutical companies are actively testing inhibitors of either IL-23 or inhibitors that target cytokines induced by IL-23 as potential treatments for AS.
SAA members like you play two significant roles in bringing our programs and services to fruition. First, you are the ones who tell us what your needs are and what tools would serve to meet them. And then, it’s your financial support that helps to make them a reality. Here are a few of the important projects your ongoing support has made possible.

**New Genetic Discoveries Bring Ankylosing Spondylitis Further Into Focus**
Since 2007, the TASC (Triple -"A" - Australo-Anglo-American Spondyloarthritis Consortium) study has been finding new genetic keys that have the potential to unlock the secrets of ankylosing spondylitis. In the last four years we have discovered thirteen new genes related to the susceptibility of AS.

As you have read on page seven of this issue, all of these discoveries combined could lead to additional targets for medications, as well as assist in developing diagnostic tests.

**SAA's Patient Self-Management Tool for Spondylitis**
Now in development with CeNRG, we are creating the world’s first cross-platform application / website that will allow people with spondylitis to track their symptoms, their medications, their medical team and appointment schedule and receive information on spondylitis through the application and SAA website.

All of this will be accessible through a smart phone (iPhone or Android) or home computer (PC or Mac). The project will be ready to launch in the early months of 2012.

**SAA Connections**
This new program gives our constituents the option to seek support via the medium they prefer most, whether it be face-to-face in a support group, one-on-one in our PEERs program, in an educational seminar setting, or online through social networking on our forums. SAA Connections brings together all of our patient support programs into one place.

**Publications**
When a person is newly diagnosed, resources and support are critical. SAA put together a comprehensive collection of resources to address the concerns of this portion of our community. The Newly Diagnosed Action Plan to Manage Spondylitis has been downloaded more than 7,000 times by those eager to learn more about living with spondylitis. From advice on choosing a rheumatologist to knowing your medications to exercise programs to tips and tricks for getting the most out of life despite spondylitis, this one-stop action plan is essential for anyone new to the challenge.

**SAA’s Screening Tool for Ankylosing Spondylitis**
Early diagnosis is the key to greater disease outcome. If the disease is diagnosed before serious damage occurs, patients can avail themselves of appropriate treatments and exercise and thereby ensure better quality of life. Since the screening tool at www.backpaintest.org was launched in July 2010, more than 20,000 people have taken the test so those with a likelihood of spondylitis can seek appropriate care.

But that’s only a fraction of what we’ve been working on. And our plans for next year are more ambitious still. All of these projects have one thing in common. They are driven by – and made possible by – you. Without the inspiration and support of SAA members and friends, none of these programs could have been undertaken. Thank you for being an involved, engaged and committed supporter of SAA!
Many Ways to Leave a Legacy

“Leaving a Legacy”. This concept appeals to many of us, recognizing that our decisions can make a difference today and into the future.

By setting up a Planned Gift to SAA, you can have confidence that your actions today will impact others for years to come. The idea of leaving a gift in your Will (Bequest) is the most common option. But there are several other options for Planned Giving. We thought it would be helpful to list the main options for you (see below), with a brief description of how each option fits different goals that you may have and how each provides different benefits to you and your family.

Please let me know if I can help. You can reach me, Mark Letts at (800) 777-8189 x. 231 or email me at mark.letts@spondylitis.org.

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<tr>
<th>Your Gift</th>
<th>Your Goal</th>
<th>Your Benefits</th>
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<tbody>
<tr>
<td><strong>Bequests</strong></td>
<td>Defer a gift until after your lifetime</td>
<td>Donation is exempt from federal estate tax</td>
</tr>
<tr>
<td><strong>Revocable Living Trust</strong></td>
<td>Make a revocable gift during your lifetime</td>
<td>You maintain control of the trust for your lifetime</td>
</tr>
</tbody>
</table>
| **Outright Gift of Cash** | Make a gift that is quick and easy             | 1. Immediate income tax deduction  
2. Possible estate tax savings                        |
| **Outright Gift of Securities** | Avoid tax on capital gains                      | 1. Immediate charitable deduction  
2. Avoidance of capital gains tax                     |
| **Outright Gift of Personal Property** | Share your enjoyment of a collection or other personal item | Charitable deduction based on the full fair market value                                                  |
| **Gifts of Life Insurance** | Make a large gift with little cost to yourself | 1. Current income tax deduction  
2. Possible future deductions through gifts to pay policy premiums                                      |
| **Gifts of Retirement Assets** | Avoid the twofold taxation on IRAs or other employee benefit plans | Allows less costly assets for your heirs                                                              |
| **Gifts of Real Estate** | Avoid capital gains tax on the sale of a home or other real estate | 1. Immediate income tax deduction  
2. Reduction or elimination of capital gains tax                                                       |
| **Retained Life Estate** | Give your personal residence or farm now, but continue to live there | 1. Valuable charitable income tax deduction  
2. Lifetime use of residence                                                                           |
| **Charitable Remainder Unitrust** | Create a hedge against inflation over the long term | 1. Receive a variable income for life  
2. Immediate income tax charitable deduction                                                              |
| **Charitable Remainder Annuity Trust** | Secure a fixed and often increased income | 1. Immediate income tax deduction  
2. Fixed income for life, often at higher rate of return                                                  |
| **Charitable Gift Annuity** | Supplement income with a guaranteed, fixed amount that is partially tax free | 1. Current and future savings on income taxes  
2. Stable income for life                                                                                |
| **Charitable Lead Trust** | Reduce gift and estate taxes on assets you pass to children or grandchildren | 1. Reduces your taxable estate  
2. Your family keeps the property, often with reduced gift taxes                                         |
Barbara Schiller held a dinner at Poor Herbie’s in Madison, NJ to raise funds for SAA and spread awareness of ankylosing spondylitis in her community. Barbara is a long time SAA member and a co-leader of the Morristown, New Jersey SAA Sponsored Support Group.

What inspired you to do the event and fundraise?
I wanted to raise money for SAA and I couldn’t make a large donation by myself. I wanted to do something for everybody. Also, I just wanted to see if I could do it!

How well did the event go?
I thought it was very successful. People came away from the dinner very educated about spondylitis. The restaurant was packed! I felt that even the newspaper articles about the event reached people and helped raise awareness. We had two local newspapers that picked up the story about the dinner along with the online versions of the papers.

What was your favorite moment?
When one of the donors walked in with roses and a large check (laughs)! One of my girlfriends surprised me - she wasn’t suppose to make the event but ended up coming with the flowers and a donation. In addition, support group members came with their families. It was such a wonderful turnout from the community.

How much did you raise?
One big surprise is that Poor Herbie’s decided to donate a portion of money from all the tables - not just those who picked up a flyer to donate. We ended up raising almost $1,400 for SAA.

Anything else you’d like to mention/talk about?
I think to pull off a fundraiser like this you have to be able to approach people and be a coordinator and delegator and to stay on top of things at all times - otherwise people may lose focus. Overall it was a great challenge and I am very happy how it turned out.

Thank you to Madison Pharmacy who donated balloons for the tables - blue balloons - that gave the event a very festive atmosphere. Thank you to Stop & Shop for donating the fruit basket we gave to the printers. Also, the corsage from SAA for Poor Herbie’s was very nice!
Jennifer Dye Visscher created the “Art Apple A Day Project” and started painting daily apples on October 1, 2010 as a way to help bring awareness to ankylosing spondylitis. You can see her work online at thefeedingedge.com. On Friday, September 30, 2011, Jenna held an event and painted in Times Square, at the Roy Arias Studios at 300 West 43rd Street. She held a 24-hour Apple-A-Thon to help increase awareness of spondylitis, raise funds and just have fun while painting.

What inspired you to do the event and fundraise?
I’m inspired every day by people who manage spondylitis. I know how difficult a diagnosis and a life with Spondylitis is because I live it too. I feel that since I have been fortunate enough to find a course of treatment that works so well for me and that I am able to work where others cannot, I had a responsibility to help in any way I could to talk about the disease and issues surrounding it. I feel we have the biggest responsibility of all to work to share our stories and become advocates and health activists, but we also need to financially support organizations like SAA. We are the ones with the most to gain by money going to education and research and I feel that we need to play a larger role.

How well did the event go?
The event went great! I was able to paint just over 100 apples in the 24 hours and we had donations of $25 for each of those apples as well as larger donations for Art Posters, multiple apples, and a very generous corporate sponsorship from BJC Connected Care in Australia. I was so amazed at the support of friends, family, fellow ASers and strangers. The efforts of Holly Sanders were phenomenal. Because Holly shared and supported the event, she was directly responsible for hundreds of dollars as well as 313 apples that children from Parker Elementary School in Houston, TX created and sent after a day in which she educated them about Spondylitis! We had a wonderful location in Times Square and some great press coverage including a television appearance on NY’s WPIX!

What was your favorite moment?
I don’t think I could say I had one favorite moment, but I loved meeting people I had met online through SAA, Facebook, Twitter and my website. I loved the first stroke of the paint brush as much as the last. I loved the experience of being on TV! I loved looking around the busy event and seeing people painting apples because they wanted to help us talk about Spondylitis and raise money for a cure. I loved seeing people creating and making art for a good cause! I was so immensely touched that people joined me in my vision to create apple art as a way of sharing our story and raising awareness. I loved running in the rain through Times Square back to the hotel after dinner to get settled in the room with my family surrounding me as I painted through the night. I loved seeing people enjoy being there to come together for us – for people with a form of Spondylitis – for a day of community and sharing in a positive and joyful way.

How much did you raise?
I am sending a check to the Spondylitis Association of America in the amount of $3750. The Art Poster will be available through the end of 2012 to continue to support SAA as they are sold.

Anything else you’d like to mention/talk about?
The Apple-A-Thon was quite an undertaking and I am so thankful for so much support from SAA and the community. There were many times it seemed overwhelming and too big to do while dealing with AS, but the support was always there and for that I am so grateful and appreciative.

I’d like to thank my friends and family who helped so much including my Aunt Debbie, my parents Bill and Susan Dye, my husband Doug Visscher, Roberta Davis (a friend of my mom’s), my brothers, as well as friends of SAA and fellow advocates Michael Smith, Tom Contrino, Anna West, and Esther Hick.
Early on in my struggle with ankylosing spondylitis, I realized that I did not want to be defined by my disease. I wanted to be seen as a person. As with most of us, it was a struggle, but until recently, I was able to do many of the things that able-bodied folk can do. As the list of things I can no longer do or enjoy inexorably grows, I try to look for creative ways to maintain my sense of humor and fight this disease. I am most proud of being able to say I taught Red Cross Swimming for the Handicapped and for almost three decades taught History in inner city middle schools. Now, I am a caregiver and I dabble in art, especially eggs.

How did I come to paint eggs? On the surface, it might seem to be an easy question to answer. In reality, I’d need to think about it. The simple answer is that my father did it. So every egg I paint is, in a small way, an honor to him. On a more practical level, it is a productive way to keep my fingers nimble and hold AS at bay a little while longer.

My father was an artist from a long line of artists. He got his degree from the Maryland Institute School of Art in Baltimore. At graduation, he was awarded a bronze medal and had a one-man display of his work. Then, he went to work for the Crown, Cork & Seal Company. They manufactured the bottle caps that you find on all manner of bottled beverages. His job was to design and paint the prototypes for the bottle caps. He actually painted them on the small metal tops.

Over time, though, cans replaced bottles, machines replaced people and my father found another line of work. His artistic talent was placed on hold. Eventually, his young niece asked him to paint something for her to enter into a contest the local library was holding. Using an egg, he created a clown holding an umbrella made from a small paper muffin liner. A new art form emerged. Over time he produced many different eggs which he always gave away. Once he painted an egg resembling “Mr. Boh” that he gave to a local baseball announcer whose tag was “Ain’t the beer cold”. (It was a different time. Mr. Boh was the “cartoon image” for National Bohemian Beer and a local brewing company that sponsored the Baltimore Orioles baseball team) His eggs always reflected something about the people to which he gave them. As an idealistic child, I guess, he reminded me of an artistic Robin Hood or St. Nicholas.

I too followed, lightly, in his footsteps and started to dabble in art. While I was in High School, I also attended the Maryland Institute, part time. There I concentrated on pastel and charcoal, again using fingers rather than a brush. Once I even had a display of my own work. Unfortunately, only one of them survives. From time to time, I still dabble with pastels but they require a level of dexterity that is rapidly slipping away.
My chosen profession afforded me an outlet for my artwork in lessons, bulletin boards and film strips for the classroom. It even gained covert attention in the form of pen & ink cartoons. They were usually created during faculty meetings to the delight of my fellow teachers.

It was not until my retirement, due to AS, that I found the time to return to painting. Many people paint pictures. It may sound somewhat selfish but like all artists, I wanted to do something unique. I didn’t have to look far for inspiration and like my father I give my creations away. From time to time I still paint, usually for a local club that is having a silent auction. But mostly, it is some kind of egg. I have painted several of them for my doctors, friends and others.

The subjects cover a wide range. I have created many animals; a duck for a local artist who carves decoys, a groundhog playing a bass clarinet (for my daughter-in-law), lambs, a Blue Crab, a lobster, turtles and many others I can’t recall.

There have also been some that one might consider a wee bit unusual. A kilted Scotsman leading a cow (my pastor’s family was from the Border of Scotland), and several doctors and nurses, even a few Santa Clauses. For a Scottish Club I painted bagpipes and for a retired military group I made a display of eggs wearing Army uniforms from 1776 to today. My nephew was very interested in The Lord of the Rings and over a period of time the entire “Fellowship”, all thirteen of them, were brought to life.

I find it very relaxing. It’s creative, fun, it’s different and it helps keep both body and mind nimble. But mostly, it makes people happy. One hasn’t lived until you have seen a doctor, white coat and all gleefully showing his “egg” to everyone on the hospital floor.

So, to return to the question “why do I paint eggs?” Maybe because AS has taken many things from me. But it hasn’t taken my ability to express myself and bring a smile to another’s face.

What creative outlet do you use to help stave off the pain of ankylosing spondylitis? If you want to share your interests with others here or online, send us your story and samples of your work to Chris Miller here at SAA:

chris.miller@spondylitis.org
As a long term supporter of SAA I would like to object to the distinct bias of your Fall 2011 article on “The Affordable Care Act: Aims to Protect Consumers” otherwise known as Obamacare, which appears to be a promotional piece for this disputed legislation.

According to the author, US presidents for 60 years have been trying and failing to “overhaul” the nation’s healthcare system. He fails to say that the overhaul intended by the Democratic presidents he mentioned in his article was to have the federal government apparatus take control over this privately managed sector of our country.

The author also highlights the goals of the healthcare act, which is “designed to expand health insurance coverage, control healthcare costs, and improve the healthcare delivery system”. He goes on to state that the Act will give Americans “control over decision making about their health coverage” and put “those with disabilities in charge of their healthcare”. He also quotes proponents saying that this legislation was developed with those of us with spondylitis in mind.

While mentioning the legislation is “controversial” he does not give any reasons for why there is the controversy. He does not mention that the act requires private citizens to buy government approved healthcare “insurance”, which many believe is clearly an unconstitutional abridgement of our freedom. He does not mention how all the supposed benefits of expanded coverage, increase personal control, and improved delivery could possibly be accomplished by the 124 new federal agencies that are going to be created to administer the Act. This doesn’t even get into the real cost of enforcement (the IRS says that it will need $1 billion more per year to administer), or expanding coverage to 30 million uninsured folks (Congressional Budget Office estimates a total of $1 trillion over 10 years), or paying for all the employees at the new healthcare agencies.

The newly appointed “Independent Payment Advisory Board” has been directed by the president to lower the cost of Medicare from the annual 6% increases of recent years down to .50% this next year. This appointed healthcare board has been given the power to reduce medical costs as they deem best which will inevitably reduce services contrary to what this article states as one of the Act’s admirable goals. By the way, it has been announced that $200 billion will be cut from Medicare Advantage this next year.

The author adds insult to injury by quoting a “healthcare advocacy” expert as saying that many spondylitis patients are “indigent or on disability due to the severity of their symptoms”. This stereotype is patently false (as can be seen on the SAA website) and insulting to most of us who are afflicted by this type of disease who are responsible productive citizens despite the pain and damage done by our disease.

Harry H. Hanger, Chesterfield VA

Editor’s Note: The article in question was presented as an informational resource for those interested in understanding the current health care act, which was signed into law, and that should it not be repealed, a timeline for how it will be implemented. That said, we do appreciate Mr. Hangar’s concerns and encourage those with questions or comments to write us in the future at info@spondylitis.org.
If you’d like to find out more about support groups or for a complete list of groups and meeting dates, visit our website at: http://www.spondylitis.org/patient_resources/

You can also contact Elin Aslanyan here at SAA by calling 1-800-777-8189 ext. 222 or by email at elin.aslanyan@spondylitis.org for more information.

Recent Meeting Highlights:

Where: Boise, ID  
When: Saturday, November 5, 2011  
Topic: Pain, Depression and Biological Medicines  
Guest Speaker: Mr. Stanley Hall, Nurse Practitioner

Where: Woodlands, TX  
When: Saturday, November 12, 2011  
Topic: Social Luncheon to kick off the Holiday Season

Where: Chicago, IL  
When: Thursday, October 13, 2011  
Topic: Coping with Spondylitis

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www.spondylitis.org
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 playing high-impact sports were over.

The Spondylitis Association of America (SAA) provided my parents with a resource through which they could cope with having a son diagnosed with ankylosing spondylitis (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.

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. SAA’s mission is “to be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to its fullest.” I want that mission to continue and flourish.

~Brian MacKenzie, Vice Chair of SAA’s Board of Directors

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