Biosimilars: What’s All The Noise About?

Anti-Inflammatory Eating: An Interview With Nutritionist, Dietician, And Author, Chloe McLeod

Raising Spondylitis Awareness
Dear Readers,

It is widely recognized that the individuals who know the most about the consequences of spondyloarthritis (SpA) on the many aspects of life—personal, social, and professional—are those directly affected by it. This group of 2.7 million individuals in the US may include you. That is why the SAA, in an effort to learn from you, conducts a SpA Life Impact Study every so many years. The results from these studies have taught us much over the years, and contributed to the direction of our organization in serving you. For example, in July 2011 we set out, with your help, to conduct a needs assessment survey in SpA. The findings of the survey and the shortcomings they revealed added further urgency to our solving the problems of delayed diagnosis, awareness, and inadequate funding for research and improved treatments. Over the years, as a result of findings from these surveys and other outreach programs, we have embarked on initiatives to meet these needs. These include international conferences to shape research, funding for novel research projects, the MRI Training Workshops for radiologists and rheumatologists, in addition to the development of the AxSpA Treatment Guidelines in collaboration with the American College of Rheumatology.

We believe that we are on the right track, particularly with regard to collaborative relationships with academia, medical institutions, and state and federal agencies, but also recognize that we still have a steep hill to climb in order to make the necessary changes to ensure that patients’ rightful expectations are secure. Future surveys will be important in showing the progress made as well as future critical challenges to overcome after careful consideration. To that end, the SAA is close to launching its third Life Impact Survey. We will be seeking your participation as SAA supporters and participants.

I would like to offer my personal thanks to all who took the time to participate in past surveys; we look forward to your ongoing collaboration. Thank you. Together we will make the future better for all of those affected.

Sincerely,

Laurie M. Savage
Executive Director/CEO
“I just read, for the second time, the Spring 2016 edition of Spondylitis Plus magazine in preparation for our support group meeting tomorrow. I think this is the most complete issue of Spondylitis Plus that I have ever read. The list of NSAIDS, DMARDS and biologic drugs currently available is great. The review of the immune pathways by Dr. Hallegua and Dr. Gensler is very helpful. The article by Dr. Rosenbaum really helped my understanding of the difference between autoimmune and autoinflammatory disease. Finally, both the recommendations from various support group leaders and the story of Jim Weatherhead’s personal struggles with AS were excellent.”

Mike Supancich
San Diego, CA

“I am a member of the SAA and was diagnosed with ankylosing spondylitis seven years ago. I am 29 years old and take Enbrel and it has been a miracle drug for me as, for the most part, it allows me to live a normal life.

I read Spondylitis Plus and enjoy how much it relates to me and the struggles I face. I haven’t written in before but found I had to send a message after glancing through Spring 2016’s Helpful Hints section and thought about my recent experience with yoga.

I haven’t been able to bend “straight-legged” and touch my toes since well before I was diagnosed with AS seven years ago. Recently my wife challenged me to start doing yoga with her before work each morning. We’re both CPAs and work up to 15 hours a day this time of year and she wanted me to give up an extra 30-45 minutes of sleep each morning in order to get a yoga session in; needless to say I thought she was crazy. Plus I didn’t know any guys who did yoga so I wasn’t too sure about the idea. I resisted at first but gave it a try and nearly quit after my first session. I ultimately agreed to a second...then third...and then I was addicted. I was surprised how difficult it was for me to do the yoga poses early in the morning with my AS but I kept with it and I found quickly how flexible it made my body. For the first time in over seven years I finally could bend and touch my toes!

It has now been five months of yoga and I couldn’t be happier about the results. I have found yoga first thing in the morning has been a great way for me to start each day and also connect even more with my spouse who ultimately wants me to be healthy and happy! It is a healthy workout each day and has helped my flexibility more than anything I’ve tried before.

Thanks for doing all you do for me and everyone else affected by AS and related diseases. I know I am fortunate to have been diagnosed at an early age and find medication that works for me and I will work to keep active throughout my life to keep the AS in check.”

Drew Adams
Overland Park, KS

LETTERS TO THE EDITOR
We want to hear from you! Send your thoughts, questions, opinions, and rebuttals.

Please send letters to:
Elin@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.
Biosimilars: What’s All the Noise About?

The biologic drug landscape shifted in March 2015 when The Food and Drug Administration approved the first of a new subclass of treatments to be marketed in the United States - biosimilars. Recently, a second biosimilar product - Inflectra (infliximab-dyyb) – a biologic drug similar to Remicade ® (infliximab) was approved. Their introduction may help expand access to high-quality treatment options for clinicians and patients and may reduce costs to families, caregivers, payers, and the healthcare system.

It has been recognized that the most effective treatments for some of the most difficult diseases in the US are biologic medicines; more so, it has been reported that the introduction of biosimilars is expected to help lower cost burdens for the US healthcare system. It also promises to provide earlier, more consistent access to these important medicines for patients with cancer, ankylosing spondylitis, multiple sclerosis, rheumatoid arthritis, inflammatory bowel diseases such as Crohn’s, and more.

WHAT ARE BIOLOGICS?

To understand the potential implications of biosimilars, both in the marketplace and in patients’ lives, it may be helpful to understand the nature of biologic drugs. Many of today’s important medications are biological products. Biological products are made from living organisms. The material they are made from can come from many sources, including humans, animals, and microorganisms such as bacteria or yeast. Biological products are manufactured through biotechnology, derived from natural sources, or, in some cases, produced synthetically. And, biosimilars are just what the word implies: similar. A biosimilar is a type of biologic that is highly similar to another branded product. It has also been called a copycat version.

Biologics are different from conventional medications. Conventional medications – compounds – are generally made from chemicals, or are chemically synthesized. Hence, their structure can be relatively easily defined and copied. Biologics, on the other hand, are many times more complex to produce than conventional drugs.

Conventional drugs are called small-molecule drugs, while biologic drugs are called large-molecule drugs. This is due to the fact that biologics are made up of big and complex molecules, often 200 to 1,000 times the size of more common small-molecule drugs. For example, aspirin, a small-molecule drug, is made up of only 21 atoms. While one of the earlier, well established biologics, which is used to treat ankylosing spondylitis and psoriatic arthritis, consists of more than 20,000 atoms.

DON’T CALL THEM GENERICs

Branded drugs fall into two basic categories: small-molecule drugs, which are usually made through chemical synthesis – breaking and reforming chemical bonds – and biologics, which are proteins made in living cells, grown in incubators, and purified from the cells, hence being substantially more complex.

WILL THERE BE COST SAVINGS?

There has been much noise suggesting that huge savings may be realized for the consumer with biosimilars vs. biologics. However, this may not be evident right away. When the first biosimilar, a white blood cell booster, came to market, it launched at just 15% lower than the brand name drug. If other biosimilar manufacturers follow this lead, discounts might not be that great, at least at first. It has been explained that this may in part be due to the fact that the spending on larger clinical trials and marketing, combined with higher manufacturing costs for biosimilars compared to generic compounds, means that biosimilars can’t be sold for similarly deeply reduced prices of small-molecule generics, which often go for 10% or less of the branded-drug price. In spite of the data available today, industry analysts have estimated a cost savings for US patients and payers in the amount of $5.7 billion between 2014 and 2024 in the case of the first biosimilar approved by the FDA. These same individuals across the investment industry are also projecting additional drugs in the biosimilar pipeline could save an estimated $250 billion over the course of the next ten years. That said, industry observers are reporting that for the time being, biosimilars likely will be priced closer to the price of the brand-name drug.
RESEARCH

WHAT IS THE APPROVAL PROCESS FOR BIOSIMILARS AND ARE THEY SAFE?

Biosimilars are licensed (approved) by the FDA when they are proven to be highly similar to an already FDA-approved biological product, known as the biological reference product, and have been shown to have no clinically meaningful differences from the reference product. Minor differences in clinically inactive components are allowed, but there must be no clinically meaningful differences between the biosimilar and the reference product it was compared to in terms of the safety, purity, and potency of the product.

It is important to underscore that the goal of the current FDA approval pathway for biosimilars is to demonstrate biosimilarity between the proposed product and the reference (brand) product, but not to independently establish safety and effectiveness of the proposed biosimilar product.

The FDA reports rigorous standards in their approval process that include:

- Analytical studies demonstrating that the biological product is “highly similar” to the brand product except for potential minor differences in inactive components
- Animal studies (including the assessment of toxicity)
- A clinical study or studies that are described as sufficient to demonstrate safety, purity, and potency in one or more appropriate conditions of use for which the brand product is licensed.

Perhaps an additional thought regarding safety might be to consider that some of the biosimilars not yet available on the US market, have been available in Europe for many years beginning in 2009, providing us with real-life patient experience with these drugs.

BACKGROUND CHECK

So how exactly did all of this come about? The Patient Protection and Affordable Care Act, signed into law March 23, 2010, amended the Public Health Service Act to create an abbreviated licensure pathway for biological products that are demonstrated to be “biosimilar” to an FDA-licensed (approved) biological product. This pathway is provided in the section of the Affordable Care Act known as the Biologics Price Competition and Innovation Act of 2009 (BPCI Act) - thus setting the stage for the introduction of biosimilars to the US marketplace.

Did You Know?

For several years SAA has been an active member of a biosimilar watchdog coalition, Patients for Biologics Safety & Access, working with other like-minded organization to ensure patient safety is observed by the FDA as the biosimilar approval rules evolve. One example of the fruit of our work is the unique four letter suffix associated with the name of biosimilar drugs. This code identifies the drug as a biosimilar vs. the original plan to have the biosimilars carry the same exact name as the brand. The coalition observed that from a patient and prescribing physician perspective, tracking was necessary to ensure patient safety.

A second issue we are currently working on is ensuring that patients who are doing well on a brand name biologic are not forced to switch to the biosimilar version for cost savings. These medications, though highly similar, are not always interchangeable, and we firmly believe that the patient and their physician should be the only ones making medication decisions.

We will keep you posted in these pages.
ADVOCACY AND AWARENESS

RAISING SPONDYLITIS AWARENESS: April, 2016

April at SAA and throughout the Spondylitis Community means Spondylitis Awareness projects galore. We offer below a snapshot of just some of the numerous awareness efforts undertaken this April.

We hope you enjoy the read!

Raising Awareness at Pri-Med West 2016: A Primary Care Physician Conference

What: Pri-Med West
When: April 28th – 29th, 2016
Where: Anaheim Convention Center in Anaheim, CA
Attendance: 7,500 physicians

SAA first had the opportunity to exhibit at this medical conference for primary care physicians in 2014, writing about that experience in the Summer 2014 issue of Spondylitis Plus. April of 2016 was our second visit to this unique conference, and this trip was just as impactful as our first.

We fine-tuned our materials, made sure to pack extra, and loaded up the car for the early morning drive down south to Anaheim.

We had the pleasure of speaking with hundreds of primary care physicians – some very aware of and knowledgeable on spondylitis, a few who had actually diagnosed a case or two of spondylitis, and many who we hoped would read the materials we provided closely and do some further research on their own as they were truly misinformed and likely to miss even the most obvious case of undiagnosed spondylitis presented in their office. THOSE experiences, perhaps more than any other, made the most striking impressions, underscoring just why we were there and the importance of the task at hand.

We distributed boxes and boxes of materials in our two days of exhibiting: materials on blood work, on inflammatory back pain and the criteria to diagnose it, on key signs and symptoms to look out for, and more. We discussed the importance of taking a thorough patient history as well as family history, of not relying on x-ray to show damage to diagnose (x-ray generally won’t show damage for the first five to ten years) and more.

We also got to hear their stories – stories of difficult diagnostic cases, of the frustrations faced by pain management specialists who feel powerless to help their patients, and the personal story of one physician who happened to have ankylosing spondylitis himself and was excited and shocked to learn: (1) that we exist! and (2) that we were there for the sole purpose of raising awareness to help bring faster diagnosis. He stuck around watching the two SAA staff members interacting with other physicians, giving out brochures and answering questions, and offering to email even more educational materials. He walked away with a big smile and an approving nod, but not before thanking us for being there and for the good service we were providing all who stopped by.

If there was ever any doubt of the value of SAA extending the resources needed to fit this conference into our stretched calendars and budgets, the experiences we brought back and the impact we are confident we made on those hundreds of primary care physicians we spoke with cleared it all away.
The idea for this project was conceived in early 2016 – to create a sharable, brief and easy to understand, yet highly informative spondylitis awareness video in an entertaining format. To have it ready to be unveiled at the start of Spondylitis Awareness Month, and to ask our community to help share it far and wide.

We worked meticulously on the script, making numerous revisions and tweaks to ensure accuracy above all, and striving to strike the right balance between ease of understanding and robust and informative content (a fine line to walk with spondylitis.) The final result, we hope, met those requirements, making it an effective awareness and advocacy tool. As for our amazing community – did you ever heed our call to share!! Our Facebook post announcing the video’s launch on April 1st reached a record breaking 120,555 people, generating 7,631 actions (reactions, comments, and shares on Facebook.) Our deepest thanks to everyone who helped in the promotion of this video! You truly were key to its success.

This project was a labor of love, and one we enjoyed working on very much. We hope YOU enjoyed it as well. And if you haven’t seen it yet – please go on over to our website today and see it for yourself. It will be located on our homepage, at spondylitis.org.

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A BRIEF HISTORY LESSON:

While you know that April has long been designated Spondylitis Awareness Month, did you also know that SAA lifetime member, tireless patient advocate, and creator of the fun and goofy website, Spondyville, Michael Smith, is responsible for spondylitis having its own month and inspiring the awareness campaigns carried out in its name each year? Michael championed the idea back in 2009 and the rest is spondylitis grassroots history.

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BUT WAIT, THERE’S MORE!

- Elsewhere, on Facebook everyone’s friend and staunch spondylitis advocate Cookie Hopper took on a 30 Day Challenge, writing about one aspect of ankylosing spondylitis each day in April. Her informative and at times poignant posts were also shared widely, reaching many people.

- And out in Baker, MT Bonnie Smith, the passionate leader of our Northern Great Plains Spondylitis Educational Support Group, attended the Southeast Montana Health Fair to exhibit to attendees, whose number neared 1,000. Bonnie reports speaking to close to a hundred people who stopped by her booth to learn about spondylitis, and giving away lots of educational and awareness materials.

Our BIG thanks to Michael, Cookie, and Bonnie, and to everyone in our community who gave their precious time and energy to speak out and raise awareness.

Did you work on an awareness project you’d like us to know about? Or have an idea for next year? Write us at Elin@spondylitis.org!
At SAA, we’re often asked why more isn’t being done to shine a light on the needs of all those affected by spondylitis. “Why has no one heard of us?” “What do we need to do to get mainstream news coverage?” “When will we get the attention we deserve?” “Where’s our Ice Bucket Challenge?”

And most importantly, “Who will fight to bring this under-recognized disease into the light?”

WE WILL. It will take all of us working together but we can create the future we want to see. The future we want our children to inherit. A future in which the word “spondylitis” is not met with quizzical looks and a shrug of the shoulders (or a look you’d expect to see when asking a dog to do calculus.)

Most of us believe that not enough is being done to focus attention on increasing federal funding for ankylosing spondylitis and its family of associated diseases. And, as a community, we’re vocal about it. But is anybody listening? The dogs might be, but they can’t really help, can they?

What we know is that, all too often, little attention is given to the impact of musculoskeletal disorders and diseases -- like spondylitis -- particularly in the areas of research and funding. Musculoskeletal disorders and diseases are the leading cause of physical disability in the United States and result in more visits to physicians that any other condition.

The economic impact of these conditions is staggering. In 2014, The Burden of Musculoskeletal Diseases in the United States (BMUS) study determined that the sum of the direct expenditures in health care costs and the indirect expenditures in lost wages was estimated to be 213 billion dollars, or 5.73% of the national gross domestic product.

You could buy 142,000 Red Tibetan Mastiffs, the most expensive dog in the world, for that kind of money. (But they still can’t do the math.)

But research funding for musculoskeletal conditions is just 1.6% of the National Institutes of Health budget. And spondylitis, specifically, gets only a fraction of that.

And, that wouldn’t buy you 101 Dalmatians.
Quite frankly, the investment in musculoskeletal research in the United States lags horribly behind other chronic conditions. While musculoskeletal diseases are common, disabling, and costly, they remain under-appreciated, under-recognized and under-resourced by our national policy makers.

At SAA, we believe that this must change. As an active and vocal member of the National Institute of Musculoskeletal and Skin Diseases (NIAMS) Coalition, SAA is working tirelessly to champion the campaign to accelerate spondylitis research. It is crucial that research funding be increased so that improved diagnostic methods and treatments can be developed.

According to the Centers for Disease Control and Prevention, ankylosing spondylitis and its associated diseases affect as many as 2.7 million American adults -- more than multiple sclerosis, cystic fibrosis and Lou Gehrig’s disease combined. But still, we’re speaking at a whisper. Or, perhaps, at a tone only dogs can hear.

As a member of the spondylitis community, you can play a leading role in changing the status quo – for yourself, your children and for all of us fighting this fight. As a patient with an existing condition, communicating the need for more research to legislators, policymakers, and research funding organizations is vital. Legislators and policymakers need you to tell them about the burden of spondylitis, how it affects you, and how important their role is in approving increased funding for research.

Another way to make sure your voice is heard is to join with SAA in its efforts to take this fight to Washington. The more resources we have, the louder our collective voice. We want to see to it that all the decision makers on “the hill” have the phrase “spondylitis research” ringing in their ears.

But we need your help to do it. You can help us pump up the volume by donating today to ensure that SAA has what it takes to keep delivering this message -- loud and clear.

Our commitment to spondylitis medical research is limited only by our resources – your donations.

As you may know, SAA asks for donations outside of the annual membership fee only three times per year, far less than most nonprofit organizations, many of which solicit funds on a monthly basis, or more. Our Spring, Fall, and Year End Appeals provide the funds we need to lead the fight to advance medical research, provide educational materials and resources, and advocate on behalf of the community we serve – your community.

As of this writing, our Spring Appeal has raised just under $20,000 that will be put to work providing programs and services to the more than 2.7 million adults in the US living with spondylitis. That’s less than ¼ of a penny to spend for each person directly affected by a family of diseases that no one else in the country is focusing on.

Please give as generously as you can. Your gift will go a long way toward providing the resources we need to stay in the forefront of spondylitis research while still providing programs and services to those affected by AS and its associated diseases. Your renewed financial commitment to SAA will help us continue the work to speed the quest for the cure. With all of us working together, we can, and will, solve the problem that is spondylitis.

Together, our voices will be heard. And we can stop asking the dogs to do calculus.
We interviewed nutritionist and dietitian Chloe McLeod, lead author of the new book, Anti-Inflammatory Eating: Recipes from Your Dietitian’s Kitchen. We thank Ms. McLeod, BJC Health, and Dr. Irwin Lim.

EA: Thank you, Chloe, for speaking with us. Would you tell us a bit about your background, what you specialize in, and what inspired you to write this cookbook?

CM: Thank you so much for having me! I am an Australian Accredited Practicing Dietitian, and have been working specifically with people with inflammatory joint diseases for the past four years. Prior to this I have had roles in community health as well as hospital based roles.

The book came about because the resource we get asked for most often is recipes. So, we thought it was time to put together a collection of quick, easy, and most importantly, tasty meal and snack ideas that aim to reduce the inflammation burden within the body.

EA: Who is this cookbook geared to? Who can it benefit?

CM: While the book came about as a result of working specifically with people with inflammatory conditions, the great thing is that nearly everyone will benefit from following this style of eating, which is very ‘Mediterranean Diet’ based. If you are interested in following a mostly plant-based, wholefood diet aiming for long-term good health, and/or you suffer from one of the many forms of arthritis - including osteoarthritis, rheumatoid arthritis, psoriatic arthritis, gout, spondylitis, or any other health issue that may result in or from inflammation - this diet can benefit you.

*Editor’s Note: The article “Insights Into The Microbiome,” found on page 14 of this issue, offers a scientific basis to the theory that adopting a mostly plant-based diet may have a positive impact on reducing inflammation.

EA: The book features anti-inflammatory foods; what are some general categories of anti-inflammatory ingredients? Are there also pro-inflammatory foods or substances to avoid? What are some examples?

CM: We have chosen to split the book up into five sections: Vegetables & Fruit, Grains & Legumes, Fish & Seafood, Nuts & Seeds, and Herbs & Spices. Current evidence-based research indicates that many of these foods and spices provide key anti-inflammatory compounds. Apart from reducing inflammation,
these foods help the whole body and its systems function better, and there is the benefit of prevention of elevated cholesterol, blood pressure and blood sugar levels. The result is better health, and for you to feel great! Examples include different colored vegetables, such as broccoli, spinach, pumpkin or cabbage; legumes, such as chickpeas or kidney beans; nuts, such as almonds and walnuts; fish, such as salmon or sardines, and herbs and spices, such as turmeric or parsley.

“If you are focusing on ‘don’t have processed food,’ as opposed to ‘include more delicious vegetables,’ it is likely you will choose what you have been focusing on.”

While the book is not vegetarian (or pescatarian, if being particular), we have included only a small selection of meat based dishes. We have avoided including any refined sugar, and recommend avoiding processed, packaged options with artificial preservatives or sweeteners as much as possible. We prefer to focus on all the delicious things that CAN be included, rather than what should be avoided, as we feel that this makes it easier for clients to change; if you are focusing on ‘don’t have processed food,’ as opposed to ‘include more delicious vegetables,’ it is likely you will choose what you have been focusing on.

EA: What specific dietary recommendations are there for people living with forms of spondyloarthritis, such as ankylosing spondylitis and psoriatic arthritis?

CM: For psoriatic arthritis, achieving or maintaining a healthy weight range is recommended, as obesity is a common problem in this condition, resulting in an increased risk of cardiovascular disease. Otherwise, nutritional recommendations for people with psoriatic arthritis and ankylosing spondylitis are very similar to those for rheumatoid arthritis. In particular, higher quality research supports use of fish oil supplements and inclusion of fish, and following a mostly plant based diet. Vitamin D levels also need to be taken into account. There is emerging evidence of the role that turmeric plays in managing inflammation in this population; although further research is required, it is still often something I recommend.

“For spondyloarthritis in general, following a mostly plant-based diet again is recommended; plenty of vegetables, fruit, whole grains and healthy fats from nuts, seeds, avocado, and fish. Again, I will often recommend avoiding highly processed foods, particularly those high in saturated fats, sugar or salt. Given the potential role of bacteria in the gut influencing these conditions, ensuring optimal gut health is also required. Including foods which promote growth of healthy bacteria, known as probiotic foods is something I also focus on with clients. This includes sauerkraut, kimchi, yoghurt, onion, garlic, asparagus and watermelon.

For this patient group it is a good idea to speak with your doctor about alcohol, and if it should be avoided. From a nutritional perspective, limiting intake is recommended.

“Given the potential role of bacteria in the gut influencing these conditions, ensuring optimal gut health is also required.”

EA: What about avoiding complex starches or gluten as a way to reduce inflammation? Is there evidence to support this, and is it something you suggest to your clients with inflammatory arthritis? Do you include low starch or gluten free recipes in your book?

CM: There is limited evidence to support this. The way I like to handle this with my clients is to recommend the higher level of evidence approach first. If this is not getting the results that we are after, a gluten free or low starch diet may be recommended. Many clients have read about these diets on forums or social media, and while the evidence is anecdotal, given there currently is not a lot else out there in relation to improvement of symptoms following these types of diets (other than a few
papers in the area which show only a modest improvement, if at all,) if an individual wants to try it, I don’t see any harm. I actually believe it is better that this be done under supervision of a suitably experienced dietitian so we can ensure that other aspects of the diet aren’t falling down, and that whole food groups aren’t being cut out unnecessarily. Given the amount of chatter online regarding the benefits, I would love to see some more research in the area so there is higher level evidence either way, so we can better help those with inflammatory arthritis.

EA: Would you share your favorite recipe from this book? What makes it your favorite?

CM: Oh this is a toughie! I love the Orange and Fennel Ocean Trout. It is such an easy recipe, and so delicious; this is on high rotation at my house. I am also a fan of the Green Granola; it’s nice and crunchy and so yummy sprinkled on yoghurt and eaten with fresh berries. And the Tofu and Herb Salad is so lovely and colorful, you can’t help but feel healthy just looking at it!

Orange, Fennel and Coriander Seed Trout

Serves 2. 15 minutes preparation time. 20 minutes cooking time.

Ingredients:
• 2 x 120 g fillets ocean trout
• 1/3 fennel bulb, sliced into big chunks
• 4 slices orange, sliced thinly
• 2 tsp coriander seeds
• Generous drizzle of extra virgin olive oil

Method:
1. Preheat oven to 180°C. (350° F)
2. Line baking dish with foil, and lightly drizzle with olive oil.
3. Place fish in an oven proof baking dish.
4. Arrange fennel around fish, then sprinkle coriander seeds over both fillets.
5. Generously drizzle with more olive oil.
6. Place orange slices on top of fish.
7. Cover with foil.
8. Cook for approximately 20 minutes.

Serving Suggestions:
Works well with Roast Vegetables with Basil and Garlic (page 90), or with the Pomegranate Salad (page 27).

Nutrition Facts:
Serving Size: 1 fillet
Calories: 394
Protein: 26.4 g  *Gluten Free
Fat: 24.9 g  *Dairy Free
Fiber: 3.8 g  *Wheat Free

The e-Book, Anti-Inflammatory Eating: Recipes from Your Dietitian’s Kitchen is sold for $9.99, and can now be purchased from SAA’s online store, with $1 from each sale being donated to SAA! Please visit StopAS.org/Store to find this book and other items available for sale.

Chloe is an Accredited Practicing Dietitian and Sports Dietitian who specializes in nutrition for arthritis and inflammatory joint disease, food intolerance, and sports nutrition. Chloe loves cooking and creating recipes, writing, and helping others improve their health.

Please note that SAA does not endorse or recommend any specific medications, diets, or products for spondylitis and always advises that you seek the counsel of your physician before initiating treatment.
Planning a summer getaway? It’s crucial to include planning for your comfort and wellbeing, and respect your body to avoid a flare up of symptoms while traveling.

Below are some general pointers to keep in mind, as well as Helpful Hints from the community. Happy and Healthy Travels!

Ensure your own comfort

Pack the important items that help you sleep and travel comfortably: any special pillows, heating pads or wraps, and any assistive devices you’ve had cause to use in the past should you need them on the trip.

Medications! Make sure you have enough of your medications to last you the trip, and pack them with you in your carry-on.

Make sure the hotel room you book has the things you prefer or require. An ADA accessible room might be a good idea in some cases - even if you don’t use a wheelchair. A hotel with a heated pool or hot tub/sauna is also something to consider for painful joints and muscles.

Pack good walking shoes and consider a foot massage and extra stretching if you’ve been doing more walking than you’re used to.

Pack along healthy snacks and drink lots of water.

Don’t overdo it

No matter what is on the agenda, schedule in rest and enough sleep; don’t push yourself too hard.

Don’t schedule too many activities for the same day. VACATION = relaxation; take some time to rest. If traveling with a group, opt out of one or two excursions/activities to allow yourself a chance to rest so that you will have enough energy to fully commit to something you HAVE to do!

No matter what is on the agenda, schedule in rest and enough sleep; don’t push yourself too hard.

Flying?

Traveling midweek decreases the chance of busy airports and long lines.

Book an aisle seat with extra legroom if possible, and take frequent stretch and walking breaks to reduce the chance of stiffness and pain from sitting too long.

Consider asking for assistance at the airport. Airlines offer pre-boarding, and motorized/wheelchair transportation through the airport to passengers who require it. Ask! Why lug along heavy items through large, busy airports? Save your energy for the fun things you want to do.

Laura suggests, via Facebook: “Schedule any strenuous activities (sightseeing in caves, hiking, even long walks on the beach) for a time when medication has taken the edge off pain, but not too late in the day. Don’t schedule too many activities for the same day. VACATION = relaxation; take some time to rest. If traveling with a group, opt out of one or two excursions/activities to allow yourself a chance to rest so that you will have enough energy to fully commit to something you HAVE to do!”

Driving?

Norma says: “I use my seat warmers on long drives; it helps keep the muscles lose and prevent them from tensing up.”

Marci: “It may take longer but I prefer driving over flying. I do use the gel cushion, squishy pillow for my back, heat, and do exercises when we stop.”

Michelle: “Neck support pillow, medications, and stops to stretch. No matter how well I am feeling when I leave, I will take both of my crutches – after sitting still for more than half an hour, I get stiff.”

Helpful Hints is a recurring feature in Spondylitis Plus dedicated to your helpful hints, tips, and tricks on different aspects of life with spondylitis.

Have a helpful hint to share with other readers? Send it in and we might publish it in our next issue. Please send your hints to Elin@spondylitis.org

Please note that SAA does not endorse or recommend any specific medications or products for spondylitis and always advises that you seek the counsel of a physician before initiating treatment. The opinions expressed in the Helpful Hints feature are solely those of our readers and our community.
 Insights Into The Microbiome: 
What You Eat Really Does Matter

By Thomas R. Collins

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The organisms in the gut are remarkably malleable with diet, dangling the possibility that diseases could potentially be affected by the food that people eat, according to an expert at the 2015 ACR/ARHP Annual Meeting.

Diet

Starting with studies of animal feces from zoos and from the wild, in which researchers found that the driving force behind their microbiome was their diet, investigators have now zoomed in to find the types of organisms that flourish in which kinds of diets, and how those communities of organisms change when the diet changes, said Peter Turnbaugh, PhD, assistant professor of microbiology and immunology at the University of California San Francisco.

His lab found, in human studies, that the changes are particularly dramatic during the consumption of an animal-based diet relative to a plant-based diet, with bacteria tolerant to bile acids becoming elevated.1

“This, we thought, was very intriguing,” Dr. Turnbaugh said. “It’s well known that if you eat a very high-fat diet, it causes your body to release more bile acids into the gut. And that can have an antimicrobial effect against many different bacteria.”

At the same time, bacteria good at degrading plant polysaccharides became less abundant.

“And so one hypothesis might be that we’ve taken away the fiber from the diet, and now these groups are starving,” he said.

The changes are particularly dramatic during the consumption of an animal-based diet relative to a plant-based diet.

There are reasons to think that these changes can have real effects on disease. A paper in 2012 showed that in mice with a diet high in certain types of saturated fat, there is an increase in the release of bile acids, with an accompanying increase in bacteria including Bilophila wadsworthia.2 And in the right genetic context, this microbe can drive inflammatory bowel disease.

In his experiments, the group that was most elevated on the animal-based diet included Bilophila wadsworthia.

“This is sort of a complicated, but interesting, way to think about this interaction between diet, the microbiome and disease,” Dr. Turnbaugh said.

Researchers then studied whether the genetic makeup of mice influenced diet’s effects on the gut’s organisms by studying mice—called Diversity Outbred Mice—that are very different genetically from one another.
All of the mice were started on a low-fat diet that was high in fiber and plant polysaccharides. When they were seven weeks old, they were put on a one-week challenge of high-fat, high-sugar diet, or the Western diet. After a week, they were put back on the low-fat diet, then were shifted to the high-fat diet for two months.

For the first few weeks, before the diet shifted, the microbiome was relatively stable, Dr. Turnbaugh said. As soon as the Western diet was started, there was “really a dramatic departure,” which then leveled out after three days. But then it “snapped back immediately” when the low-fat diet was resumed.

“This was really surprising to us—despite the fact that these mice are all very genotypically diverse, their microbiomes seemed to be responding very similarly,” he said.

The lab also found that the changes in the microbiome seem to be dose dependent, with the extent of dietary changes appearing to dictate the extent of the changes to the gut’s organisms.

Researchers in his lab are now looking at the effects of food preparation on the microbiome.

“We now know that diet plays a major role—if not the dominant role—in shaping our microbiome,” Dr. Turnbaugh said. “These changes are important, both in terms of changing the structure of the community and also their function.”

Helminths

Joel Weinstock, MD, professor of medicine and gastroenterology at Tufts University, described his lab’s work in trying to glean insights from the way helminths, worm-like parasites, affect the immune system, in an effort to find new therapeutic approaches to inflammatory bowel disease—insights that could eventually translate to rheumatic diseases.

Helminths used to be in everyone’s gastrointestinal tract, but not anymore; they have fallen away with modern-day sanitation. Those who carry helminths have different immune characteristics than those who don’t; for example, there are differences in responses to vaccinations.

Through a series of experiments in mouse models of inflammatory bowel disease, researchers have found that infecting them with worms limits inflammation compared with those that have not been infected. Adaptive immunity is blocked at two points by the worms, Dr. Weinstock said, by dendritic cells at one point, and by regulatory T cells at another.

He said that, by determining how worms modulate host immunity, the medical world may be able to use this knowledge to develop new approaches to help control immune-mediated diseases.

“The key thing is that the worms have had 100 million years to figure out how our immune systems work and how to modulate our immune function,” he said. “We’ve been at it only 100 years. We are trying to find drug targets that could be effective at controlling disease.”

“Understanding how these organisms work to regulate us to protect themselves from immune attack may afford us new insights into pathways of immune regulation useful in controlling disease. We may find molecules in worms, or perhaps there are molecules already in the pharmaceutical industry, that can target these pathways, which will help at controlling inflammation in the gut or elsewhere.”

References


Seventeen months ago I went from being the chronically ill person in my marriage, to simultaneously being a caregiver. I have been living with spondylitis and rheumatoid arthritis for over 23 years. Just to keep things interesting, my husband’s genes decided to trigger and he developed severe Celiac Disease that is still not well controlled. Our world quickly turned into being able to speak the same autoimmune ‘language’ – a language you never want someone you love to know.

Luckily, my years of experience helped us. I was able to expedite my husband’s testing, diagnosis, and plan for treatment. Expedite is the nice way of saying I put my foot down, and demanded what we needed. If we didn’t get what we needed, a doctor or two found themselves fired.

My husband hates the word “caregiver” and I have my hunches why. He’s always prided himself on being able to take excellent care of me, of being able to make my life easier. But to suddenly instead be the one who needs, now that’s a different story.

But maybe I am wrong, so I asked him. The discussion did not head in the direction I expected. What I learned from interviewing him, is that more than anything, we as a society need to look out for the caregivers in the world. Just be there for them. And those of us who have diseases? We need to give our caregivers time to decompress, and let them escape. It’s only fair, seeing as I try to do the same.

After this conversation with my husband, I plan to find more ways to ‘escape’ together, to relax, to focus on just being us as people, not patients. That way we are more mentally recharged and able to care for each other and meet the challenges at hand.

So, I present to you, a discussion with my husband on our ever-expanding roles as people who have chronic illnesses and are caregivers:

Me: Why do you not like using the word “caregiver?”

J: It feels like it implies I can’t do anything for myself, when in reality I can do almost everything for myself. In our marriage, I am still doing most of the caregiving. When I go down in a bad way, I can’t. When you’re there and offer help, of course I’ll take the help. I view it as we’re married and we take care of each other.

Me: So what would you call it when I take care of my brother or mother who also live with chronic diseases?

J: Sister, daughter, or even friend. To me it doesn’t seem like it needs its own term. This is just what we do.

Me: What was it like to be the healthy one in our marriage for so many years, and caring for me?

J: Hyper-stressful. Stress to the point of maybe triggering my own problems. In no way is it a small undertaking.
less money you have, the more stressful it is. The unhealthy person was working the most, and I was trying to support you through that, while also trying to find a steady job.

To be honest, I hated that time in my life. It didn’t help that I didn’t like where we were living, and our environment. I didn’t have support, because no one understood the kind of undertaking it is. Even my family and close friends don’t understand.

**Me:** Have you thought about asking your friends and family for support?

**J:** I feel like I can’t ask them for support. I don’t feel entitled to support. If there was a better understanding of our situation, then it would have been easier to accept the support. I just wish people would do it on their own instead of feeling guilted into supporting the caregiver, or feeling like they have to do it.

**Me:** What does it mean to “do it on their own?”

**J:** I’m only referring to our inner circle of people. It’s not about understanding our diseases per se – it’s about understanding the undertaking our combined health is in our lives. Just a little understanding. So I could call someone for support if I ever needed to.

“**My husband hates the word “caregiver” and I have my hunches why. He’s always prided himself on being able to take excellent care of me, of being able to make my life easier. But to suddenly instead be the one who needs, now that’s a different story.”**

**Me:** What would that support look like?

**J:** I don’t know, haven’t had it!
Me: Are you talking about mental support, or physical support – like bringing a homemade meal over?

J: Just lending an ear. Someone I can vent to, that’s really all I need.

Me: Do you think there is a way our doctors could help facilitate better support?

J: No. I think it would be too much on top of what they already have to deal with in their jobs.

Me: What could I have done better to help you when you were the only caregiver in our marriage?

J: Honestly, I’ve never thought about that. It’s in the past, and I would rather move forward. I prefer to think of what I can do more now, what I can control.

“We as a society need to look out for the caregivers in the world. Just be there for them.”

Me: So often my health is out of control, how do you feel during those times?

J: At times I felt helpless. Here in Los Angeles I don’t feel helpless. The doctors we used to have were never up to par with the severity of your diseases – they were never going to get you the help you need. We weren’t going to routinely drive six hours for better doctors. Now, we have access to better doctors. That gives me peace of mind. I don’t think we think about that enough. That our current location gets us excellent care.

Me: Do you think the access to better healthcare reduces your burden as a caregiver?

J: Your doctors here are willing to take risks and make decisions. That gives me physical stress relief, but also mental support – I’m not the only one fighting for your health.

Me: How has caregiving changed for you since you’ve been sick?

J: Depending on the day it can be harder. If you really need a lot of caregiving, and I’m not feeling well, it can be tough. Whoever is feeling the worst gets the most care.

Me: What have we learned in our marriage since you got sick? Do you think we communicate better? Perceive each other’s needs better? Make the day-to-day easier for each other?

J: That. That’s exactly what I was going to say.

Me: So at the end of the day, what do you think has changed now that we both live with autoimmune diseases?

J: I feel like we’re emotionally closer.

Me: Yup. I completely agree. What advice do you have for other caregivers?

J: Why worry, we’re all gonna die anyways.

Me: That’s a little morbid!

J: I’m still just taking it one day at a time, I’m still learning. Take it one situation at a time. When you get a health event behind you, don’t keep thinking about it. Move forward with life.

Me: What one way do you care for yourself as a caregiver?

J: I try really hard not to think about the things I have to do as a caregiver. That’s probably another reason I don’t like to think of myself as a caregiver.

Me: Let me ask that another way, what hobbies help you relax?

J: Watching sports or movies, listening to records – anything to take my mind off it, and just be me, and not a caregiver for as long as I can.

Me: This isn’t the discussion I expected, lol!

J: Well, you wouldn’t have wanted to marry me if you always knew what to expect from me!

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