

Amy Ramirez- My Story:

In 2011, due to ongoing allergies, I sought out an Allergist who happen to also be a Rheumatologist. During her thorough initial exam, she asked standard questions regarding overall health, including bowel health. I indicated that I had experienced trouble in that regard for many years. She recommended that I go to see a Gastroenterologist and get a colonoscopy.

Meanwhile, she ordered a barage of lab work. One of the lab tests showed that I was positive for the gene HLAB27. This gene is linked to Ankylosing Spondylitis, and a high percentage of individuals with Ankylosing Spondylitis also suffer from some form of IBD (Inflammatory Bowel Disease) or IBS. A subsequent Colonoscopy confirmed that I did, indeed, have Crohns Disease.

She asked if I ever had back pain. I confirmed that I have had back pain for decades, but always attributed it to my moderate Scoliosis. X rays at this time did not reveal fusing of the SI joints or spinal vertebrae yet, a classic sign of later stage AS. However, it can take 10-15 years after the manifestation of AS before there is radiological evidence of fusing. If you catch the disease early enough and begin immediate protocols to slow down the activity and progression, you may never experience the fusing.

An MRI, however, did reveal the beginning of destruction by arthritis in my left SI joint, as well as the beginning of calcification of the ligaments in my neck on the right side. At this point I was given the status of "Pre-Ankylosing Spondylitis", being in the very early stages. The pain in my back and neck, as I mentioned, was normal to me by this point and was not significantly impairing my life YET. So I declined the medications that my Doctor mentioned as options after reading about their horrible side effects and weighing the risk versus the benefit. I was not ready to take that step yet and commit to drug therapy. I decided to wait until the time came when I felt my life WAS being impaired by the disease, if that time ever came.

The time came only one year later, in 2012. I woke up one morning completely unable to move without the most intense excruciating pain that I had ever felt, located mainly in my SI joints, but it radiated into my butt and up into my low back and down my legs. The pain felt similar to knife stabs and twists. If I moved even one inch I screamed in agony. On a scale of 1 to 10, my pain was an 11. I could only lie there in bed and cry, wondering what was wrong. I could not sleep due to the pain. I could not roll over, and just getting out of bed was a night mare. I dreaded having to go to the bathroom, for it meant both getting up, walking a short distance, crouching down to sit and standing back up again. Each of these actions meant guaranteed torment.

The traditional pain relievers over-the-counter that I had on hand did absolutely nothing at all. I had to sit up in bed at night because laying down hurt even more than sitting up. The pain grew tremendously during the night. In the mornings I could not move. As the day wore on, the pain would gradually subside from an 11 to an 8 or 9. I would have a window of perhaps 2 or 3 hours during the day with this "reduced pain", and then about 5 pm the pain would start creeping back up again.

What was going on? I thought perhaps I had injured or hurt my back or hips somehow, and it would pass in a few days with bed rest and ice. It did not pass. In the back of my mind the fear was growing....could this be due to that Ankylosing Spondylitis thing that my doctor told me about? And what is the connection between AS and Crohns? Was there anything natural that I could do which would help my situation, to prevent me from having to rely on drugs (I am certainly not opposed to drug therapy, but I am a firm believer and exploring all options and using drugs as a last resort, not a first), or minimize the dosage of drugs? I realized that I needed to get more information.

Once I was able to sit up in bed, the first thing I did was take my laptop and begin searching for information. I wanted to know what scientific research was being done, and find out about any discoveries that had been made recently, and not just in the United States, but worldwide, both for Crohns Disease and for Ankylosing Spondylitis. This is where I feel my journey really began.

First, starting with Crohns research, I kept coming across information about a diet called the "Specific Carb Diet" which had been a tremendous help to many in Canada who had Crohns Disease. The diet basically eliminates all complex carbs (starches and grains). It is based on the work of Dr. Sidney V. Haas, MD, in New York City. His diet was brought back to the public's attention in more recent decades by Elaine Gottschall when she wrote the book "Breaking the Vicious Cycle". After coming across the diet by Dr. Haas, Elaine Gottschall implemented it immediately to treat her daughter, who was, at this point, almost at death's door. She was desperate, and amazed as she watched her daughter finally heal and become effectively cured, by simply altering her diet. After this, Elaine was inspired and motivated to enter the halls of academia and the research laboratory herself at the age of 47. She earned degrees in biology, nutritional biochemistry, and cellular biology before going on to write her book.

The diet is based on scientific evidence (even more abundant today than it was when Elaine Gottschall wrote her book) that IBD is caused by an imbalance of intestinal flora. By altering the foods we consume, we can affect the constitution of the flora so that our intestinal tracks can heal. Our diet, particularly carbohydrates, plays an enormous role in the type and quantity of

our flora. When foods are not fully digested or delayed in digestion, they become food for the flora that lives there.

Simple carbs, which require minimal effort for digestion and do not linger long in the large intestine, are absorbed more quickly and leave little behind to provide a food source for the harmful bacteria. These simple carbs are "monosaccharides". They include only single molecules of sugars (glucose, fructose and galactose) that do not require enzymes in order to break them apart and split them into single molecules. They already ARE single molecules. So our bodies quickly absorb them. These simple carbs are found in fruits, honey, most vegetables and yogurt.

Double sugar molecules (2 molecules stuck together), are called "disaccharides". They include lactose and sucrose. They require enzymes to split them apart for digestion. Sucrose is typical white table sugar. Many people lack the enzyme to break apart the lactose ("lactose intolerant") and sucrose. Yogurts and hard cheeses that are well aged contain very little or no lactose because the bacterial culture (probiotics) found in them have digested the lactose already for you and broken apart the 2 simple sugars that are attached. This is why certain cheeses and yogurts are allowed on the Specific Carb Diet (SCD). In fact, these products are very important in the diet as they help to re-populate the digestive tract with healthy bacteria and resolve the imbalance.

After reading this information, I went on to look for research regarding Ankylosing Spondylitis. Then I came across the work of Dr. Alan Ebringer. He worked as the Professor in the Department of Rheumatology at The Middlesex Hospital UCH School of Medicine and Infection & Immunity Group, Division of Life Sciences, Kings College, London, UK and ran the Ankylosing Spondylitis Research Clinic there. His research and experiments on AS spanned decades and led him to the undeniable conclusion that AS is caused by intestinal flora in genetically pre-disposed individuals. More specifically, the Klebsiella bacteria is the culprit. People with a particular gene (HLA-B27) might react to this bacteria in a dysfunctional way. The Klebsiella microbe has molecules which resemble HLA-B27. Therefore, when the dysfunctional immune system creates antibodies against the bacteria, it also creates antibodies against the patient's own body. The SI joints, back, and eye end up being targets.

Dr. Ebringer's further research led him to realize that a low starch diet, allowing only simple carbs and no complex carbs, will deny the Klebsiella bacteria nutrition. Starch is their primary food source. He found this is the best way to keep this harmful resident microbe at bay and prevent its proliferation. The Klebsiella require complex carbs, or starches, which do not easily

or quickly digest, for sustenance. Therefore, Dr. Ebringer developed the "London Low Starch Diet" which eliminated most starches, grains and complex carbs. Sound Familiar?

"ISN'T IT INTERESTING," I thought, "THAT 2 DIFFERENT DOCTORS, WHO ARE WORLDS APART, ARE BOTH RECOMMENDING THE SAME DIET PROTOCOL FOR MANAGING 2 DISEASES THAT ARE KNOWN TO BE RELATED.....AS AND CROHNS?"

I knew that it was also an established fact that a higher-than-average percentage of individuals who had AS ALSO had some kind of IBD, such as Crohns. But doctors were not sure what the connection was.

Dr. Ebringer found out by researching Crohns also that Klebsiella is involved in that disease process as well, and the low-starch or no-starch diet is appropriate for that condition too.

I didn't know if the diet would work for me, but I was determined to try it. I knew it wouldn't HURT to give it a go. It's a healthy way of eating. So why not? What have I got to lose? I told myself that if starch is the problem, it will never again touch my lips! This put ME in the driver's seat.

I began the diet that very day, adhering to it very strictly (the diet does not work if you only do it somewhat. It requires complete compliance to work). Within 3 days I noticed a difference. My pain went from an 11 to a 7 (for some people it takes several weeks or even up to 2 months to see the difference. My case was much faster). This was so encouraging that I stuck with it. Over the next several weeks my pain slowly decreased. At the same time, I felt my body adjusting to living without starchy carbs. I would still eat simple carbs, so this was not a "no carb diet", although the carbs were definitely reduced from what they were before. When you cut out all breads, rice, potatoes, corn, legumes, etc, you are reducing your carbs for sure. I still put honey in my coffee. I ate fruits. I ate low starch veggies and I ate plenty of fiber. Those were all carbs. And I increased my protein and healthy fats.

I learned from research that your body will eventually learn how to convert fat into energy instead of relying on carbs. But the body takes a little while to go through this conversion. How long it takes varies from person to person. For some, a few weeks is all it takes. For others, it

takes a few months. Meanwhile, you may not feel great. I would get dizzy and feel tired and hungry (my body was having carb withdrawals). But I stuck with it, knowing this was to be expected. I also learned the importance of increasing my FAT intake since my body now needed to rely on fat for energy. I ate avacados, nuts, coconut, olives and olive oil, etc.

That initial withdrawal period passed, and I started having more and more energy and less and less pain. Within a couple months I was in full remission with no symptoms, normal SED rate and normal C Reactive Protein. My Crohns improved at the same time that my AS was improving and I achieved remission for both conditions at the same time.

I was so grateful for finding this information that I felt it was my duty to share it with others. At the same time, I thought I may as well also share any other resources, tools and information I have come across that might help my fellow AS Community. When I was first diagnosed, I went through stages of shock, denial, fear, panic, and desperation. I was frantically searching for anything which could help....direction, information, guidance. I felt lost and alone. I did find the help I need, thanks to many other people (Dr. Ebringer, Carol Sinclair, KickAs.org, and my friend Evie who has had AS for many years). I cannot fail also to thank God above, for I had been praying for wisdom and direction. I also found help from doing much research Online, paying particular attention to the published scientific studies. Here and there, spread out everywhere, I found useful help and tools and information and products from many different places over a period of a number of years. I wanted to bring all of these together for you in one place and save you the time and trouble, reducing your “learning curve”.

I feel that it is important that we stay united and help one another. Only each one of us truly knows what the other is really going through.

But this website is not to share my journey ONLY. I want you to share yours. Let your voice be heard!