



FROM DENIAL TO SUPPORT:

One Writer's Story by Philip S. Donlay

I walked out of the doctor's office stunned, armed with several brochures and a million questions. I'd just been informed that I was HLA-B27 positive. This genetic discovery, coupled with the x-rays taken of my spine three weeks earlier, left the doctor little doubt that my pain and suffering was due to a disease, ankylosing spondylitis. With those words, my twenty year history of pain and seemingly random ailments all fell into perfect focus. Whether I liked it or not, I was now in a group.

On one hand, I felt some relief. Through sheer force of will, or maybe even downright stubbornness, I'd forced my enemy out of the shadows into the light. This disease could hide no longer and I firmly believed that I could overcome this and regain control of my life. One by one I read the brochures I'd been given. The first one was about the disease itself; I saw words like brittle bones, spinal fusing and aortal valve leakage. As hard as I looked I found nothing about a cure. Online, the digital world brings me grim story after story. This is not a kind disease; I read testimonials and cautionary tales about people who live with long term chronic pain. This can be a terrible disease, one that will ravage your bones and joints for as long as you can draw a pain filled breath. After hours online, squinting into one medical paper after another, all I felt was alone.

The more I read, the more I hope to find some other affliction that fits my symptoms. I don't want AS. What I don't grasp yet is that I'm going through the initiation process. I'm a rookie, and this is only the first step in a long transformative process. The experts call it denial, and I'm buried deep in its clutches.

I set up appointments for a second opinion. I'm angry and little scared, and the medical industrial complex will have to stop and listen. If I were honest with myself, what I've done is set up appointments to find a different diagnosis. I have twenty years experience with doctors not getting it right, why should I believe them now? I only need to keep looking and find a diagnosis that sends me into a different group, a different affliction, perhaps one that doesn't even warrant a brochure.

The weeks and months drag by and every road I travel leads me back to AS.

An outbreak of iritis seems to mock me, and at some point I begin to fully grasp that the whole denial thing probably isn't working. I have to accept that I have AS and it's devouring all of the good parts of my life. I've been a complete jerk to most everyone I know. I deserve to be avoided. I'd avoid me if I could. The friends I still have, look at me suspiciously, and say. "You look fine." I try to explain that I don't have any energy, that my joints feel like they have the flu and I am so tired I could sleep on bare concrete. The invitations slowly dwindle and my world shrinks dramatically.

“After hours online, squinting into one medical paper after another, all I felt was alone.”

For nearly two years, I flounder in my group of one. The medications fail and the AS worsens. I endure heart surgery and watch helplessly as most of the things I love fall out of reach. Through my own fault, I lose important people along the way. My group of one is toughest on those close to me.

I finally decide that battling AS through the Minneapolis winters was an ordeal I didn't have to endure. With connections in Dallas, I feel confident that whatever anemic winter Texas might throw at me would be microscopic compared to Minnesota. In Texas I'm around old friends, and before I can alienate them with my caustic, AS fueled sarcasm, I follow up on a promise I made to myself that I'd attend the Dallas support group sponsored by the SAA.

As an author, I would not generally categorize myself as a group person. I'm more like a loner, even a hermit. At times I've been called a recluse as I sit at the computer screen for as long as I can, doing the dance with words that will eventually become a novel. It's solitary work this novel writing and therefore I've never been one to give much thought to groups. As a rule I don't belong to any group; I pay no annual dues to an organization that would require me to be at a certain spot on a given day.

As the day of the meeting drew near, I gave myself a dozen opportunities to chicken out. I'd been a group of one for so long I will readily admit to being a little uneasy about the whole process. Where I need to go is an hour away via eight-lanes of rush-hour hell, but a promise is a promise. As I played stop and go with the masses, I decided this was stupid, everyone who knows me knows I don't do groups. I hate traffic and I don't do groups. Who was I kidding? The last thing I needed was to go hang out in a room full of people as grumpy and bad-tempered as myself. Still, I soldiered onward.

I held my breath and pushed through the door and found myself standing in an empty room. I'd come all this way and I was still a group of one. Moments later, a smiling red-haired woman walked into the room. She introduced herself as Rachel, the group leader, and yes, I was in the right place. Rachel was a blur of motion as she continued setting up the room, so much so that I highly doubted she had AS. Which made sense, why would anyone put a grouchy, pain addled, sleep-deprived person in charge of anything important? We chatted and she asked me when I was diagnosed, then she replied that we were diagnosed at almost the exact

same time. I'd just met the first person on the planet besides me who suffered from AS, and we were nothing alike.

More people began to arrive, and my anxiety slowly went away, replaced with an eagerness to get to know this handful of fellow human beings. Rachel stood before us and told her story. I learned that Rachel's motivation to become a group leader revolved around what AS did to people. "There is inevitable loss—there isn't anyone who isn't changed by this disease. Losses can be anything from mild lifestyle changes, to life altering events. Whatever the case, no one should have to go through this alone." Rachel said, and then went on to tell us that she was in the process of setting up a website for the group, as well as a Facebook page. What she had in mind for possible future meetings. I knew then that we were in very good hands.

I listened intently as people described their own personal journeys. Each story was as unique and complex as the person doing the telling—or as unique and complex as this disease. I've tried two different TNF blockers to no avail. I learned I wasn't alone, yet there were others who relished the improvement these drugs provided. I was curious about those in the room who'd been fighting the disease for years. Perhaps I could get a glimpse into my own future?

Besides the people who'd been diagnosed, there were also a mother and a husband in attendance, and both remarked that they were glad they came—that the group point-of-view helped them better understand the disease.

Rachel ended the meeting by making it clear that we were the group, not her;

she was simply the facilitator and her phone was always on.

It has been months since my first meeting and I still marvel at the experience. I've left Dallas, but I still stay in touch with members of the group. Though far away, their presence is still reassuring. I, like most others afflicted with his disease have been subject to a variety of treatments, some benign, others brutally painful. Some worked, most didn't. But I can honestly say that one of the best treatments I ever received was going from my little group of one, to belonging to an entire community. For the better part of twenty years, as I chased the root cause of my symptoms, I'd known concern, sympathy, even compassion, but among those strangers in Dallas who become my friends, I found something that had been missing...empathy.

“Each story was as unique and complex as the person doing the telling—or as unique and complex as this disease... I learned I wasn't alone...”

Author's Note: *SAA-Sponsored Educational Support Groups serve members of the spondylitis community in 24 states across the US. The process that SAA requires for its group leaders is impressive. There are applications, followed by evaluations to determine subject knowledge, motivation and personal history. The final stage is an interview with an SAA Board Member. Please do yourself a favor and use every asset SAA provides, including the wealth of information available at www.spondylitis.org. I encourage everyone touched by this family of diseases to reach out and make a connection. Remember, no one need go through this alone.*