You might think that as a Registered Nurse with access to doctors and medical information, I would have a quick path to diagnosis,” tells Jane Bruckel, BSN, RN to Spondylitis Plus. “You’d be wrong.

35 years ago, a small group of AS patients changed the course of spondyloarthritis, and jump-started its research in the U.S. This is SAA’s “Your Story,” which begins with a personal need, and a woman named Jane Bruckel.

“You might think that as a Registered Nurse with access to doctors and medical information, I would have a quick path to diagnosis,” tells Jane Bruckel, BSN, RN to Spondylitis Plus. “You’d be wrong. After eight painful years, I was finally diagnosed with ankylosing spondylitis. At first, I was relieved to finally have a name to my pain. But where was the information I so desperately wanted? My nursing textbook on diseases had one small paragraph on AS! I needed to understand what I was in for the rest of my life, and what I could do to help myself. Where were other people with the disease? As my husband and I were looking forward to having children, I especially wanted to talk to a woman with the disease. I felt frustrated and angry, isolated and alone.

I was fortunate to be accepted into a two-week fellowship program offered at UCLA through the Arthritis Foundation. The program was taught by, and for, arthritis health professionals like RNs, PTs and OTs. It was a wonderful, intensive program that exposed me to all aspects of the rheumatic diseases, including ankylosing spondylitis. But none of the presenters could answer my specific questions and none had encountered women with AS. My frustration grew.

Out of this sense of frustration and isolation, I finally asked my doctor if he would invite his AS patients to a support meeting. Simultaneously, another AS patient asked his doctor to do the same. And so, about 12 of us met for the first time in January of 1983, creating the country’s first-ever AS support group.

We were all excited to finally meet. And women, too! We found that we’d all experienced this sense of frustration, anger, and isolation. We decided to meet monthly. As word got out, our numbers rapidly grew and with that growth the need to create an organization focusing on AS became clear. We selected a board of directors, called ourselves ‘The Ankylosing Spondylitis Association,’ and went into fast gear.”

What was going on in the Ankylosing Spondylitis landscape back in 1983?

“The short answer is nothing was going on. No publications for patients, no way to connect with other AS patients (no internet, no support groups, no organization), and the number of researchers and amount of funding going to AS research was quite small. There was very little interest among rheumatologists, and absolutely no public awareness.

Everything we did from there on was a first in the U.S. Six months after our first gathering, we launched a quarterly newsletter. It had to be put together the old way. Articles were typed, then cut and pasted into a storyboard, then sent off to the printer to finish. We held monthly meetings with guest speakers, such as rheumatologists, physical therapists, experts in medical and social security disability insurance, etc.

Then, a whole new world suddenly opened up to us. A physical therapist just back from a two-week AS course in Great Britain told us that AS organizations existed in countries throughout
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Europe! She introduced us to the British organization, NASS, which shared their patient publications with us, helping us create our own. Soon after, we were among the founding organizations of the Ankylosing Spondylitis International Federation, a worldwide organization that, among other things, is charged with helping AS organizations. Imagine, from not knowing anyone else, to having a worldwide AS connection!

As ASA grew, and took more and more of Jane’s time, Jane realized she needed to leave her nursing job to devote herself fully to the young organization’s mission. The Board authorized a salary, enabling Jane to become its first official employee. She learned to write grant proposals and began fundraising in earnest. She tells Spondylitis Plus about the first large grant she wrote - applying to the Dallas based Harold Simmons Foundation for $50,000 to go towards an AS awareness campaign. It was rejected. Not one to give up, Jane flew to Dallas to meet the foundation’s representatives and personally deliver the revised draft of the grant. It was accepted, and went a long way in helping raise the organization’s profile.

Shortly after, the first AS public service announcement was created - which featured Ed Asner, perhaps best known as the newsman, Lou Grant, from The Mary Tyler Moore Show. Various publications printed pieces about AS and the association, and the ASA was finally on the public radar. In fact, the publicity resulted in so many calls and letters that the young association had to hire its second official employee – an administrative assistance to handle the inquiries. The U.S. Spondylitis Community was forming, and ASA was at its epicenter.

The 80s also saw the publication of the first comprehensive book for AS patients “Straight Talk On Ankylosing Spondylitis,” the start of ASA’s Medical and Scientific Advisory Board, the first (and second) patient and physician scientific symposiums on AS, and ASA’s first steps into the research arena - which would shape the next big chapter for the organization.

The 90s and beyond – Research is King

While we can’t possibly fit into this piece the numerous research milestones accomplished, we will briefly touch on a few early items that were key to shaping SAA’s future.

In 1992, The Ankylosing Spondylitis Association (ASA)
In 2003, the FDA was considering approving Enbrel as the first biologic drug indicated for AS. As an advocate for SAA, I was invited to testify. I brought with me numerous testimonials from our members who, like me, were already taking the drug off-label.

changed its name to the Spondylitis Association of America (SAA) to reflect a broadened mission encompassing the totality of spondyloarthritis - the family of related diseases.

In 1995, SAA’s Board of Directors changed the organization’s major focus to spearheading and funding research efforts into uncovering the causes of and cure for spondyloarthritis.

That same year, a leading gift of $30,000 from the Jean and E. Floyd Kvamme Foundation, and Damon Kvamme kicked off SAA’s fundraising for spondyloarthritis research. With mission and now funds aimed at research, Jane connected with the National Institutes of Health (NIH), meeting with NIAMS Director, Dr. Stephen Katz to discuss future collaborations and SAA’s commitment to research. A fruitful relationship was formed that has served SAA and the spondylitis community for decades since.

Just three years later, in 1998, SAA would fund Drs. Reveille and Jin to start the first major, nationwide AS genetic study. The year after that, the NIH would recognize the importance of this work, providing a $6.5 million grant for the study, as well as designating SAA as a clinical coordinating center. The AS Family Genetic Project had taken form, which would morph into the international Triple A Australo-Anglo-American Spondyloarthritis Consortium (TASC), and go on to eventually identify two additional genes in 2008 - ERAP 1 and IL23R - that play a role in susceptibility to spondyloarthritis. A huge breakthrough for spondyloarthritis research.

We end our story as we have begun it - with Jane, who shares one last memory.

“In 2003, the FDA was considering approving Enbrel as the first biologic drug indicated for AS. As an advocate for SAA, I was invited to testify. I brought with me numerous testimonials from our members who, like me, were already taking the drug off-label. They told heartfelt stories of how the drug gave them their lives back and many told of the hardship since their insurance wouldn’t pay for it. I came prepared to tell some of these stories and to tell my own story. Since I had never disclosed which biologic I was taking, I planned not to specify the drug I was on. The panel of experts listened to testimony from researchers and a young man with juvenile AS who had also been invited to speak. Between each speaker, I listened to the panelists discuss some of their thoughts. At one point, I found it hard to believe hearing them debate whether Enbrel should only be approved for early disease and only for men. I could hardly contain myself. So, when I got up to testify, I read from the letters as planned. But I went on to disclose to the panel that I also take Enbrel and that it has changed my life. I told how, after years of walking very gingerly, I could now run down the street, run up and down stairs (not recommended), and how I was so elated at the change that I even showed our friends at New Year’s Eve that I could jump rope! (Also not recommended). I then emphasized to the panel that “I’m a woman, and I’m NOT newly diagnosed!”

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Enbrel would soon be approved for all adults with active AS, and Jane would be quoted in the press release announcing the very thing she helped make possible. Though retired, Jane is never far from SAA (or its staff) and remains an invaluable resource. “Since my retirement 12 years ago, I am overwhelmed by the achievements and incredible impact this organization has continued to make under the leadership of Laurie Savage (who herself has recently retired). Way too many to mention! Laurie kept us moving forward at a fast pace. I believe this forward momentum has been possible because she and the Board of Directors stayed very focused on our mission. I am confident that our new CEO, Cassie Shafer, has the ‘know-how’ and enthusiasm to continue this fast-paced march toward finding a cure, and empowering those affected to live life to the fullest. I look forward to seeing all they accomplish in the next decade to bring us closer to our ultimate goal of ending this disease forever. And in the meantime, continue advocating on our behalf, and improving the quality of our lives.”